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Walden University

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LaTrina Frazier

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Review Committee
Dr. JaMuir Robinson, Committee Chairperson, Public Health Faculty
Dr. Cynthia Tworek, Committee Member, Public Health Faculty
Dr. Susan Nyanzi, University Reviewer, Public Health Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
2015

Abstract

How Spiritual Values Correlate With Hospice Use for African Americans

by

LaTrina D. Frazier

MHA, University of Phoenix, 2005

BS, University of Phoenix, 2002

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health

Walden University

February 2015

Abstract

End of life hospice services have consistently been underused by African Americans. This disproportionate use of hospice has contributed to poor quality of life and a lack of cost-effective care for patients with terminal illness. Driven by the theory of reasoned action, the purpose of this quantitative study was to test associations between African Americans' perceptions of hospice, decisions to use hospice, and religiosity. A convenience sample of 154 African American adults was surveyed online. The survey instrument combined the AARP End of Life survey, Perception of Hospice survey, and the Religiousness Measure survey. The results of a multiple linear regression showed a significant relationship between religiosity and perception of hospice where those who reported a higher level of religiosity had a more favorable perception of hospice ($B = .174$, $p = .041$), whereas there was no support of a relationship in which religiosity was a predictor of intent to use hospice ($B = -.019$, $p = .816$). Findings also showed the more positive the perception of hospice the lower the rate of intent to use hospice ($B = -.181$, $p = .002$). This research could benefit health care providers, researchers, and community members by increasing public awareness and education of hospice. Focus on the underuse of hospice by African Americans may promote positive social change through discussion within communities and hospice agencies about the barriers to service; these results may also foster implementation of interventions and initiatives that improve service to underserved populations. Such efforts could improve quality of life for individuals, their families, and communities.

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Dedication

This study is dedicated to my noni (Magnolia), my papa (Milton), and anyone who is ever faced with the decision of using hospice.

Acknowledgments

I would like to thank my Lord and Savior, Jesus Christ, for the blessing and opportunity to complete my dissertation. I would like to thank my friends and family for your love, support and encouragement, with a special thanks to my husband (Eric) for showing interest and the long nights of allowing me to read to you; my sister (Latisha), my brother (Gregory II), and my sister-in-law (Lakisha) for listening to my endless conversations about my topic; my parents (Gregory Sr. and Sherilyn) for praying for me, supporting me, and giving continuous words of encouragement; my in-laws (Dorothy, and R.T.) for your support and encouragement; and my grandmother (Mordess), who has always shown interest in everything I have done. I love you all. I would finally like to thank Dr. JaMuir Robinson and Dr. Cynthia Tworek for your words of encouragement, support, and guidance during this process. I have definitely been challenged and grown under your instruction.

Table of Contents

List of Tables v

Chapter 1: Introduction to the Study 1

Introduction 1

Background 2

Problem Statement 4

Purpose of the Study 5

Research Questions and Hypotheses 5

Theoretical Framework 6

Nature of the Study 7

Definitions 7

Conceptual Definitions 7

Operational Definitions 8

Assumptions 9

Scope and Delimitations 9

Limitations 10

Significance of the Study 11

Summary 12

Chapter 2: Literature Review 14

Introduction 14

Literature Search Strategy 15

Theoretical Framework 16

Barriers to Hospice 17
Knowledge 20
Access 21
Trust 22
Culture 24
Religiosity 26
Religion and Hospice 28
Strengths of Current Studies 28
Weaknesses of Current Studies 30
Summary 32
Chapter 3: Research Method 34
Introduction 34
Research Design and Rationale 34
Sample 35
Sample Size Calculation 35
Procedures for Recruitment 39
Data Collection Procedures 39
Instrumentation 40
Data Analysis 43
Threats to Validity 47
Human Subjects Protections 48
Summary 49

Chapter 4: Data 50

Introduction 50

Pilot Study 50

Data Collection 51

Participant Characteristics 52

Results 54

Research Question 1 56

Research Question 2 59

Research Question 3 61

Research Question 4 66

Summary 68

Chapter 5: Discussion, Conclusions, and Recommendations 69

Introduction 69

Summary of Study Findings 69

Interpretation 71

Limitations of Study 74

Recommendations 75

Implications 77

Conclusion 78

Appendix A: AARP Letter of Permission 86

Appendix B: National Oklahoma City Douglass High School Alumni Association Permission 87

Appendix C: Religiousness Survey Permission..88

Appendix D: Hospice Perception Survey Permission 89

Appendix E: Letter of Invitation..90

Appendix F: AARP End of Life Care Survey 93

Appendix G: Religiousness Measure..97

Appendix H: Hospice Perception Survey 99

Appendix I: Demographic Survey 100

Appendix J: Participant Survey 100

Curriculum Vitae 108

List of Tables

Table 1. Variable Relationship Measures: Religiosity, Perception and Intent to Use Hospice 46

Table 2. Demographic Frequencies and Percentages 53

Table 3. Descriptive Statistics: Number and Percentage of Hospice Importance 54

Table 4. Descriptive Perception of Hospice Number, Percentage 55

Table 5. Intent to Use Hospice Demographics (*N* = 154) 56

Table 6. Religiosity, Perception of Hospice, and Intent Descriptive Mean, Standard Deviation 56

Table 7. Correlation of Religiosity, Perception of Hospice, Age, Sex, Marital Status, Education, Income 57

Table 8. Regression Analysis of Religiosity and Perception of Hospice 58

Table 9. Regression of Religiosity, Perception of Hospice, Age, Sex, Marital Status, Education 58

Table 10. Correlation of Intent to Use hospice, Perception of Hospice, Age, Sex, Marital Status, Income, Education 60

Table 11. Regression Analysis of Intent to Use Hospice and Perception of Hospice 61

Table 12. Regression of Perception and Intent to Use Hospice 61

Table 13. Correlation of Religiosity, Intent to Use Hospice, Age, Sex, Marital Status, Income, and Education 63

Table 14. Regression Analysis of Religiosity and Intent to Use Hospice 65

Table 15. Regression of Religiosity and Intent to Use Hospice 65

Table 16. Correlation of Religiosity, Perception of Hospice, and Intent to Use Hospice 67

Table 17. Regression of Religiosity, Perception, Intent 68

Chapter 1: Introduction to the Study

Introduction

Hospice has become a major entity within the healthcare system that has proven to effectively manage patient symptoms and healthcare cost at the end of life. Hospice care is a service available to persons who have been identified as terminally ill. This comfort care is offered when there are no further treatments available toward a cure for the medical illness. Hospice services were first used in the United States in 1974, with the opening of the first American hospice (National Hospice and Palliative Care Organization [NHPCO], 2010). Since that time, there has been a push for increased public awareness and understanding of hospice's role in healthcare. Hospice services focus on quality of life as opposed to length of stay or quantity of days for patients. Hospice services are covered by most private insurances, Medicare, and Medicaid (Haas et al., 2007). The philosophy of hospice is to ensure that the patients receive individualized, competent, and specialized care while facing the dying process (NHPCO, 2010).

End of life is often the most expensive time of care in a person's life. For this reason, hospice has been seen as a benefit to the healthcare community by helping control cost of care for individuals (Johnson, Kuchibhatla, & Tulsky, 2011). Patients have been known to spend countless hours or even days receiving treatments that are ineffective and inappropriate for them at the terminal phase of their disease. Ineffective aggressive medical treatment has been identified as a contributing factor to the rising cost of healthcare (Washington, Bickel-Swenson, & Stephenson, 2008). Aggressive treatment

often costs the patient money and convenience without the benefit of favorable results (Barnato et al., 2009; Quest et al., 2011). For this reason, hospice has been seen as a benefit to the healthcare community by helping control the cost of care (Johnson et al., 2011). This study provides information that could facilitate interventions and information that may improve the use of palliative care at the end of life in order to enhance patient quality of life and decrease health care expenses. This study could also impact the policies associated with end of life care, increase public awareness, and identify the correlation of religion and African American perceptions with decisions about hospice use. Global interventions and initiatives that may increase overall hospice use and awareness could also result from this study, thereby bringing attention to the barriers associated with hospice. An explanation and brief background of hospice are presented in this chapter, along with elaboration of the research problem and quantitative research study purposes, as well as the research questions, theories, definitions, research assumptions, and limitations of the study.

Background

In 2008, 38.5% of people who died had been enrolled in hospice services, with 35% of those being enrolled in hospice service for 7 days or less (Vig et al., 2009). Reports estimate that the African American senior population will have increased by 217% between 1990 and 2020 (Haas et al., 2007). It has also been estimated that by 2050, members of ethnic minority groups will comprise 50% of the U.S. population (Kennedy, Mathis, & Woods, 2007; Taxis, 2006). As the African American population increased, it was expected that African American representation in hospice enrollment would have

also increased (Taxis, 2006). Among African Americans who accepted hospice care, 62% were discharged from hospice for aggressive treatment, personal reasons, or a preference to die in the hospital (Ludke & Smucker, 2007). Chilton et al. (2008), Fishman et al. (2009), and Haas et al. (2007) also identified a disproportionately low representation of African Americans who died on hospice services as intended by the Medicare benefit model. Furthermore, there was a significant difference reported in the length of service between African Americans and Caucasians who elected hospice service use (Hardy et al., 2011; Kennedy et al., 2007; Ludke, & Smucker, 2007; Volandes et al., 2008).

The lack of growth in African American hospice enrollment and use has created a disparity in hospice care that affects African American end of life care negatively (Austin, & Harris, 2011). African Americans are more likely than Caucasians to die in the hospital, citing religion, knowledge of hospice, mistrust, or culture as the reason for their choice (Chilton et al., 2008; Connor, Elwert, & Spence, 2008; Hanson, 2009). Consequently, in 2009, the percentage of African American patients who elected hospice care at the end of life was lower than that of Caucasians and lower than the current African American population representation of 12.4% (Webb, & Tucker, 2009). Some African Americans refuse hospice services when they have been suggested, while others do not receive information about end of life care because of physician opinion, preference, or interpretation of patient religiosity (Ache et al., 2011). No studies have been conducted on how religion, perception of hospice, knowledge of hospice, mistrust, or culture affect African American hospice use, resulting in a research gap (Hardy et al., 2011; Johnson, Kuchibhatla, & Tulsky, 2009; Yancu, Farmer, & Leahman, 2010).

Problem Statement

African Americans have been noted to use hospice services at a lower rate than Caucasians, which has impacted the cost of healthcare and quality of life for African Americans (Fishman et al., 2009; Haas et al., 2007). Poor knowledge, mistrust, and cultural and religious barriers have been identified as factors impacting rates of hospice use among African Americans (Ache et al., 2011; Johnson, Kuchibhatla, & Tulsky, 2008; Kennedy et al., 2007; Ludke, & Smucker, 2007; Vig et al., 2009, Volandes et al., 2008). Despite the fact that the spiritual support component is a required service that is offered to all patients by hospice providers, religion has been identified as a barrier to hospice use (NHPCAO, 2010). There is a lack of published data that quantify the association between these barriers and African American hospice use.

In 2010, approximately 1.56 million people accepted hospice services (NHPCO, 2010). The percentage of people who do not receive quality care at the end of life continues to be highest for African Americans. Among those enrolled in hospice, the percentage of African Americans is 8.7%, compared to 80.5% for Caucasians (NHPCO, 2010). African Americans are 83% more likely than Caucasians Americans to be in acute care settings as opposed to hospice care, which is thought to be a more cost-effective form of end of life care (Johnson et al., 2011). No research has quantified the role of poor knowledge, mistrust, cultural, and religious barriers on hospice use in general. Furthermore, no data were found that assessed the extent to which religiosity affects intention to use hospice specifically among African Americans.

Purpose of the Study

The purpose of this quantitative study was to determine the association among religiosity (independent variable), perception of hospice (mediator), and hospice use (dependent variable) among a sample of African Americans, and to identify whether there is any correlation among religiosity, perception of hospice, and intent to use hospice. This study also addressed gaps that had been identified in previous research in relation to reported low hospice use rates by African Americans and perceived barriers to hospice use. In this study, I attempted to quantify the associations among (1) perception of hospice and religiosity, (2) perception and intent to use hospice, and (3) religiosity and intent to use hospice, in order to provide additional information to aid in the understanding of the underuse of hospice services by African Americans. Another goal of this study was to determine whether perceptions of hospice explained an association of religiosity and intent to use hospice by African Americans.

Research Questions and Hypotheses

1. What is the association between religiosity and perceptions of hospice among African Americans?
    - $H1_0$: There is no association between religiosity and African American perceptions of hospice.
    - $H1_1$: There is an association between religiosity and African American perceptions of hospice.
2. What is the association between intent to use hospice and perceptions of hospice among African Americans?

- $H2_o$: There is no association between intent to use hospice and perception of hospice.
- $H2_1$: There is an association between intent to use hospice and perception of hospice.

3. What is the association between religiosity and the intent to use hospice among African Americans?
    - $H3_o$: There is no association between religiosity and African American intent to use hospice.
    - $H3_1$: There is an association between religiosity and African American intent to use hospice.
4. Do perceptions of hospice mediate the association between African American religiosity and intent to use hospice?
    - $H4_1$: Perceptions of hospice do not mediate the association between religiosity and intent to use hospice.
    - $H4_2$: Perceptions of hospice mediate the association between religiosity and intent to use hospice.

Theoretical Framework

The theory of reasoned action (TRA) was selected in order to identify the impact of subjective religious views on intentions and decision to use hospice among African Americans. The theory of reasoned action concerns intended behaviors; through this theory, one can gain an empirical understanding of intention (Fishbein, & Ajzen, 1975).

It is believed that knowledge about a person's intended actions assists in accurately predicting behavior. A more detailed explanation of TRA will be presented in Chapter 2.

TRA was the preferred theory because I was looking at the association of religiosity with use of hospice service among African Americans. Similarly, Enguidanos et al. (2011) used TRA when reviewing how the use of role-model stories would impact African American attitudes and influence to use hospice. TRA has been used in social research studies concerning expected behaviors and predicted actions or reactions. In the studies reviewed, TRA was rarely used to explore hospice care. The use of TRA gave empirical identities to these associations and intention to use hospice.

Nature of the Study

This cross-sectional quantitative study was designed to examine African American intentions to use hospice and perceptions of hospice based on level of reported religiosity. The study involved surveying African American adult members of the National Oklahoma City Douglass High School Alumni Association through convenience sampling. Data were collected through Survey Monkey, an online survey instrument, using the AARP End of Life Care (EOLC) Survey, Religiousness Measure, Hospice Perceptions Survey, and a demographic survey.

Definitions

Conceptual Definitions

Terminal: "A life expectancy of six months or less if the illness runs its normal course" (NHPCO, 2010, p. 3).

Palliative care: Care that has a "focus on easing the severity of disease symptoms while enhancing the quality of life for patients confronting a serious or life-threatening illness" ("Navigating Palliative Care," 2007, p. 9).

Disparities: "Reflect grave inequalities that require remedies so that social justice prevails, regardless of race" (Austin, & Harris 2011, p. 133).

Culture: "Integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious or social groups" (Egede, 2006, p. 668).

Spirituality: "An acknowledgement and a relationship with a supreme being" (Quinn, & Guion, 2010, p. 4).

Operational Definitions

Hospice knowledge: "Understanding the mechanics of hospice services" (Yancu et al., 2010, p. 249). Hospice use was measured based on Questions 10, 11, 12 and 13 of the AARP EOLC Survey, which addressed knowledge of hospice service in general (Straw, & Cummins, 2003).

Religiosity: "Religious attendance, practice and activity" (Quinn, & Guion, 2010, p. 4). The variable were measured by review of emphasis on religious service attendance and participation, based on the answers provided to Questions 1, 2, 3, 4, 5, and 6 in the Religiousness Measure survey tool (Appendix G; Sethi, & Seligman, 1993).

Intent: "The extent to which an individual plans to engage in the behavior" (Enguidanos et al., 2011, p. 162). Intent to use hospice was measured based on a positive

or negative response to Question 7 of the AARP EOLC Survey, which addressed the desire to use hospice services if dying (Appendix F; Straw, & Cummins, 2003).

Perceptions: “Beliefs and attitudes” (Johnson et al., 2008, p. 1956). Perceptions of hospice were measured in this study based on responses to Questions 6, 8, 10, 11, and 12 of the Hospice Perception Survey (Appendix H; Van Dussen, Culler, & Cagle, 2011).

Assumptions

It was assumed that hospice is a form of healthcare that delivers quality, efficiency, and symptom management to patients in an expedited and cost-effective manner (Johnson et al., 2011; Yancu et al., 2010). It was also assumed that the survey participants were answering the questions honestly, based on their own ideas. There was also the assumption that hospice is a desirable form of care that is beneficial in terms of quality of life and cost effectiveness. It was also assumed that the identified barriers to hospice, which included poor knowledge of hospice, lack of access to hospice care, lack of trust in the healthcare system, low rates of minority professional representation, culture, and religion, were accurate.

Scope and Delimitations

African Americans were surveyed. The study was open to any African American adult who was at least 18 years old. This study did not compare length of stay, enrollment rates, or duplication of enrollment into hospice. This study did not focus on any specific religious denomination. This study was not intended to identify interventions that would enhance hospice enrollment. There were also no studies found that allowed for comparison of selected statistical test methods. This study was not designed to identify

any previously unidentified barriers that might have greater influence than religiosity, or perception of hospice on African Americans' decisions about hospice use.

Limitations

One limitation of this study was that the individuals being surveyed were not necessarily facing a decision about hospice. This study focused on assessing intention to use hospice and not actual hospice use. This was a limitation because the study concerned intent and not actual decisions that had been made, resulting in estimation of the individual choice for or against hospice. Individuals have the ability to change their minds as a result of circumstances or knowledge, at any time. This study was conducted with people who answered questions based on their expected behaviors and how they perceived that they would respond if faced with the decision to use hospice services. Social change implications could be limited by respondents choosing not to use hospice after reporting a decision to use hospice.

Other limitations were related to the survey being conducted online and the sample being drawn from one organization in one area, which might restrict general inferences about African American perception and religiosity. Because this study was conducted online, the ability to generalize these findings to individuals who do not actively use the Internet or do not have Internet access may be limited. There was no follow-up activity for clarification of responses. The use of a convenience sample of the population may have also limited the generalizability of the study findings. Unwillingness of prospective participants to complete and submit the survey may have resulted in limited representation of portions of the African American population. In a

study conducted by Johnson et al. (2008), 32% of African Americans participated in surveys while 68% declined to participate in studies. The data were collected over a 2-month period in order to promptly share data. Biases that might have affected this study may have included participants' choice to give answers that they perceived me to be looking for instead of their true perceptions. The participants' desire to provide more socially acceptable responses could have also resulted in biases being present.

Significance of the Study

This study is significant, as it provides information that could lead to the development of interventions to increase hospice use rates, as well as information on how hospice services coincide with religion, which may support increased use of hospice services by African Americans. The results of this study may impact social change within the African American population by providing information to the National Hospice and Palliative Care Organization, the Hospice Foundation of America, and religious organizations that could lead to the development of global interventions to increase hospice use rates. The study provides an analysis of the association between religion and perception of hospice, intent to use hospice and perception, and religiosity and intent for hospice use, as well as an analysis of whether perception mediates any of these associations. The results of this study could increase support for use of hospice, and the study may highlight areas that are serving as barriers to hospice use by African Americans. Additional implications of this study are that it may provide better understanding of religiosity within the African American community, which would also be beneficial to health care professionals who are caring for African American patients.

Increasing African American hospice enrollment would create access to comfort at the end of life for patients who are deemed terminal. It would also give additional information that would help to decrease the amount of money that is spent at the end of life for patients who are not expected to improve or recover from their illnesses. This may be accomplished by this study identifying the relationship between hospice use and religion among African Americans and the perception of hospice via survey.

The information that has been gained through the survey will add to the data that have been collected on the ways in which religiosity has served as a barrier to hospice utilization by African Americans. The data has also given any correlating factors that would affect hospice enrollment, such as perception, religious affiliation, and intention to use hospice. This study provides more information about the associations of hospice enrollment, perception of hospice, and religiosity, to identify whether religiosity or perceptions may impact intent for hospice enrollment.

Summary

In recent years, hospice has been seen as an entity that serves the senior population and cancer patients (Ache et al., 2011). Due to advances in healthcare technology, there are many forms of treatment that are aggressive in prolonging life (Barnato et al., 2009). This is especially important with the increased number of Americans under the age of 65 being diagnosed with terminal illnesses (Quest et al., 2011). This chapter has addressed the role of hospice in healthcare, the use of EOL care for African Americans, and the underuse of hospice by African Americans. This chapter has also identified the limitations and purpose of this study. Chapter 2 contains an

overview of the literature regarding perceptions of hospice use, barriers to hospice enrollment, African American culture and religion, and the search strategies associated with the literature review.

Chapter 2: Literature Review

Introduction

This chapter contains a review of the literature on religiosity, hospice use, and barriers to hospice use. Literature that addresses access to hospice and healthcare, racial and ethnic disparities in hospice, attitudes about hospice services, and African American culture and religion as they relate to hospice is also reviewed. The objective of this literature review was to gain information and proceed with the development of a research study concerning the intended use of hospice services to determine whether religiosity is correlated with African American hospice use.

Hospice programs are forms of supplemental care that provide end of life care focused on symptom management and education to the patient, family, and caregiver. In order for a patient to qualify for services, at least two physicians must agree that it is possible that the patient's disease could result in the patient's death in 6 months or less (NHPCO, 2010). End of life care uses a holistic approach to care for enrollees' social, psychological, emotional, physical, and spiritual needs (Connor et al., 2008; Quest et al., 2011). The overall goal of hospice is to provide symptom management, patient caregiver support, education about expected disease progression, and a peaceful death experience.

Hospice is used by fewer than half of the people who die in the United States (Enguidanos et al., 2011; Quest et al., 2011). The reported rate of use is even lower for African Americans. African Americans are twice as likely compared to Caucasian Americans to decline hospice care (Connor et al., 2008; Hanson, 2009). The underuse of hospice by African Americans has been a problem. Despite the development of

successful interventions, the interventions have not been widely accepted by African Americans and have thus been unsuccessful at increasing overall rates of hospice use (Connor et al., 2008; Enguidanos et al., 2011; Johnson et al., 2011).

Literature Search Strategy

Initially, the search was very broad and included any article that addressed hospice and end of life care. This produced a large number of results. The search was then refined and given parameters of 2005 to the present, in April 2012. After review, the search was given another stipulation of 2007 to present. Additional search terms—*African Americans, Blacks, minorities, terminal, palliative care, barriers, resistance, obstacles, healthcare, community health, faith, religion, religious, spiritual, spiritual values theology, church attendee, church attendance,* and *access*—were also used in conjunction with the term *hospice use*. Other searches were conducted over the course of 3 months using the terms *decision, refusal of service, impact, effect, affect, death and dying, culture, attitude, healthcare utilization, racial and ethnic groups, sociocultural factors,* and *healthcare awareness.* There were 211 articles reviewed. When several criteria were applied—peer review, years of 2007-2012, and written in English—the number of articles was reduced to 92. The literature had to address *hospice disparity, barriers to hospice, access to healthcare, minority perceptions, religious and spiritual perceptions of healthcare*, and *perceptions of hospice care* for inclusion. Forty-two articles met the criteria for inclusion at that point. The number of articles was reduced further after relevance and pertinence to the subject were identified.

Databases used to search for articles included PubMed, EBSCO, CINAHL, PsychINFO, SAGE, Ovid, MEDLINE, ERIC, and ProQuest. Searches were conducted online using the Walden University library, Google Scholar, and the public library. The review was intended to identify hospice policies, philosophy, care issues, methodologies, and theories associated with African American hospice use and the correlation of religiosity on the choices associated with low rates of use. The articles were to address hospice disparity, barriers, access to healthcare, minority perceptions of health care, and religion/spirituality for African Americans.

Although I would have preferred to limit the articles to those published in 2008 or later, this would have resulted in very little information. There has not been a significant amount of information published on barriers associated with African American underuse of hospice. In order to provide a detailed inquiry, 2007 literature was reviewed for consideration. Hospice is not an area that had been widely studied in reference to use among African Americans.

Theoretical Framework

The theory of reasoned action (TRA) was the theoretical framework used to support this study. This theory was initially developed by Fishbein in the 1960s. Azjen partnered with Fishbein, and they refined the theory (Fishbein, & Azjen, 1975). This theory addresses the concept that behaviors can be predicted by an individual's reported intended behaviors. TRA has been selected because of the need to identify the relationship of reported religiosity and its impact on decisions for hospice services among African Americans. In past studies, "TRA has been used for the purpose of prediction and

explanation" (Ross, Kohler, Grimley, & Anderson-Lewis, 2007, p. 124). The primary purpose of this study was to look at the factors associated with hospice use.

Manstead (2011) identified that there were several domains that made TRA valid. Studies have been conducted on safe-sex intentions, oral health, seat belt use, and habits associated with behavior with the use of TRA (Manstead, 2011; Ross et al., 2007). Being able to predict behavior and the factors associated with intentions was expected to assist in better understanding African American decisions. This was significant for the hospice study because participants might not have been diagnosed with a terminal disease or had to face a decision about hospice services.

The ability to identify intention greatly improves the capability to associate the likelihood of hospice use and perception of hospice with religiosity. Ross et al. (2007) used TRA to understand and obtain information on what motivated African American men to seek information on prostate cancer from a physician. TRA has indicated that "intention is directly influenced by an individual's general attitude toward a behavior and his subjective norm regarding the behavior" (Ross et al., 2007, p. 124). In order to get an idea of the effects of religiosity on the use of hospice services by African Americans, the intended use or attitude toward hospice must be reviewed. This study assessed factors associated with intention, with the assumption that intent predicts behavior.

Barriers to Hospice

Research has identified multiple barriers associated with the underuse of hospice services by African Americans. These barriers include poor knowledge of hospice, lack of access to hospice care, lack of trust in the healthcare system, low rates of minority

professional representation, culture, and religion (Volandes, & Paasche-Orlow, 2007; Yancu et al., 2010). The barriers cited in the literature are not clearly identified or defined but are discussed in vague terms. Articles that identified the use of focus groups reported the validation of poor knowledge, access to hospice, lack of trust, low professional minority presence, culture, and religion as barriers (Enguidanos et al., 2011; Fishman et al., 2009; Kennedy et al., 2007; Washington et al., 2008). There were also no studies found that ranked the barriers in order of their impact on hospice use or prevalence. Washington et al. (2008) conducted a literature review that identified barriers to hospice use as being in conflict with African American cultural and spiritual values. This study included a literature search of published articles on African American hospice use. These findings indicated that African American resistance to hospice use was perceived as a religious conflict, despite explanations of reported benefits (Washington et al., 2008). It was also found in this study that there was a need for more specification concerning how the barriers pertained to African Americans and hospice use, in order to understand what were viewed as incomplete data concerning the barriers to African American hospice use (Washington et al., 2008). The study by Washington et al. confirmed that there were barriers to hospice use.

Overall rates of African American patients who access hospice have been considered low, although there have been reports of an increase in hospice service access (Connor et al., 2008). According to Connor et al. (2008), African Americans had a hospice use odds ratio equal to 0.59; $p < .001$ when compared to Whites. It was also reported that African Americans were 75% more reluctant than Caucasians at 51% to

discuss a referral to hospice; $p = .002$ (Ache et al., 2011). This showed statistical difference in the use of hospice between African Americans and Caucasian Americans. According to the National Hospice and Palliative Care Organization (2010), there continues to be underrepresentation of African Americans in hospice, and the barriers to providing information to the African American community remain unchanged, with African Americans representing 8.7% of the hospice population. This rate has stayed in the eighth percentile since 2000 (NHPCO, 2010). These statistical data were also misleading because they include duplicated admissions.

The studies reviewed consistently identified barriers to hospice use of religiosity, mistrust, poor knowledge, and culture (Ache et al., 2011; Vig et al., 2009). African Americans have also been noted to have the highest proportion of aggressive health care treatments at the end of life (Barnato et al., 2009; Webb, & Tucker, 2009). Individuals were surveyed about their preferences for aggressive treatment, using surveyors to administer a verbal interview without modification of the questions. This created difficulty in identifying the correlation of barriers associated with the underuse of hospice by African Americans. Conjoint interviews were conducted by Fishman et al. (2009) with $N = 283$ African American and Caucasian American cancer patients who were actively receiving treatment. Fishman et al. had a goal of 20% of the survey population being African American. A total of $n = 81$ (9%) were African American, and $n = 202$ (71%) were Caucasian (Fishman et al., 2009). Fishman et al. found that although many of the African Americans interviewed had a poorer prognosis and as well as a need for hospice that exceeded the benefits of treatment, they were still more likely to continue with care,

thereby creating a disparity in hospice service use (Fishman et al., 2009). Because Fishman et al. only had 9% participation from African Americans as opposed to the desired 20%, the results may not be generalizable.

Knowledge

Lack of knowledge about hospice services has been offered as another explanation for poor hospice use (Volandes, & Paasche-Orlow, 2008). Studies conducted between 2009 and 2012 determined that the African American community has a low level of understanding of the services of hospice (Enguidanos et al., 2011; Vig et al., 2009; Volandes, & Paasche-Orlow, 2007; Yancu et al., 2010). This was even true of those who had reported having experience using hospice for a family member in the past. It has been found that more Caucasians have awareness of hospice services in comparison to racial/ethnic minority populations (Volandes, & Paasche-Orlow, 2007; Yancu et al., 2010). In a study conducted with young adults (N = 419), 48% (n = 203) of African Americans surveyed had no knowledge of or experience with hospice, as compared with 59.4% (n = 366) of (N = 616) Caucasian Americans (Webb, & Tucker, 2009). Knowledge was not found to be an independent predictor of hospice use. According to Webb and Tucker (2008), hospice knowledge and past experience did not increase choices to use hospice services. African American knowledge deficits were also attributed to the lack of hospice presence in the African American community (Haas et al., 2007; Hardy et al., 2011; Vig et al., 2009). These articles that addressed poor understanding of hospice philosophy also addressed access to hospice care by African Americans. Johnson et al. (2009) addressed knowledge as a barrier by exploring the

beliefs and values that impact hospice use. Difference in thought about hospice was researched using a random survey among those who reported having knowledge of hospice.

Access

According to Hanson (2009) African Americans were reported to have less access to hospice care, $p = .0004$, with less exposure noted in a study involving African Americans ($n = 105$) and Caucasian Americans ($n = 95$). Out of 220 African American adults surveyed, 89.5% ($n = 197$) reported poor exposure to hospice (Hanson, 2009). Poor access among African Americans has been linked with all aspects of health care and is not unique to hospice (Washington et al., 2008). Although many initiatives have been put into action, poor access to hospice has continued to be cited as an issue for African Americans (Volandes, & Paasche-Orlow, 2007). Volandes and Paasche-Orlow (2007) conducted an empirical study of health literacy and quality of care. The researchers correlated low health literacy with increased risks of death (Volandes, & Paasche-Orlow, 2007). Hanson (2009) used a longitudinal study of cancer patients in the advanced stages to assess and compare access to care among African Americans and Caucasians. Hanson’s study identified that factors of socioeconomics, poor health education, social inequity, culture, and trust individually impacted poor access to hospice. The results suggested that there needed to be a focus on connecting interventions of quality care and advanced diseases.

Trust

Many African Americans have reported having poor trust in the healthcare system and healthcare professionals (Washington et al., 2008; Yancu et al., 2010). African Americans have held the position that healthcare workers are not aware of their healthcare needs and that healthcare practices do not reflect the core values of African Americans (Yancu et al., 2010). African Americans have also been noted to delay healthcare until emergent care has become imperative or overdue. Research has identified that African Americans' mistrust of healthcare has been linked to the perceived complex process of accessing healthcare. Armstrong et al. (2007) examined the relationship between race and mistrust of primary care physicians. In the analysis, no control variables were used. African Americans had a mistrust level of 16.5 on a trust scale of 0-20, which was significantly higher than the level of Caucasian Americans at 15.2 ($p < .001$). Other studies also noted that there was significance among use of healthcare services and mistrust of the healthcare system (Armstrong et al., 2008; Kennedy et al., 2007; Washington et al., 2008). Yancu et al. (2010) noted that increased hospital visits were linked with poor trust of healthcare workers and the view of receiving inferior care, although no analysis on possible racial variations was conducted.

Low representation of African Americans among hospice professionals has been linked with mistrust of hospice (Kennedy et al., 2007). Kennedy et al. (2007) cited no statistical data but referenced reports by the American Nurses Association, which made reference to the Department of Health and Human Services (DHHS; 2009). According to DHHS (2009), 4.2% of 2,909,357 registered nurses were African American. There were

no data found that gave a breakdown for African Americans working specifically in the hospice profession, making it unclear as to whether the number of African American professionals in hospice is actually low or whether patients perceive it to be. African Americans surveyed in a study by Fishman et al. (2009) also reported less trust in the information provided on hospice service. Although African Americans were reported to have a greater need for hospice, 59% (n = 48) of African Americans compared to 43% (n = 86) of Caucasians reported that they were 100% likely to continue cancer treatment if deemed terminal in a small convenience sample survey (Washington et al., 2008). This low level of trust has been traced to the Tuskegee Syphilis Project conducted by the Alabama Health Department, which resulted in the unnecessary death or sterility of many African American males, due to treatment being withheld once available (Johnson et al., 2008). In addition, many African Americans were not told the truth about the study upon enrollment.

For many African Americans, these past experiences have resulted in fear that information or treatment would be withheld simply because of race. Webb and Tucker (2009) surveyed college students in a beginning-level psychology course in order to determine how race, gender, hospice knowledge, and experience with hospice impacted perceptions of hospice, with inconclusive findings. The study did identify that 55% of those surveyed reported negative experiences with a dying loved one and preferred hospital care to home care. Ludke and Smucker (2007) conducted a random telephone survey which reported that 62% of African Americans surveyed would prefer to die in the

hospital than to die in hospice care as a result of mistrust of hospice services, compared to 8.2% of Caucasians.

Taxis (2006) conducted two focus groups using a total of 28 adults to explore reasons for African American underuse of hospice and identified primary barriers to hospice use as poor information, culture, and the health care system. This study did not associate culture with fear. According to Taxis (2006), the barriers were categorized as differences in values. For this reason, African Americans have been reported to have the highest incidence of intensive care unit placement, when no further treatment was appropriate; because of a refusal to stop treatment (Chilton et al., 2008; Washington et al., 2008).

Culture

Culture has been identified as a barrier to hospice use for African Americans. Studies have found that culture and religion impact attitudes when hospice was addressed (Ache et al., 2011; Yancu et al., 2010). Culture has been used to refer to a variety of concepts but has not been specifically defined. Yancu et al. identified culture as a key indication of how people would govern their life, including health. There was a lack of knowledge noted on cultural differences and attitudes towards death and dying. This study found that after measuring the reasons for hospice use and cultural concerns, cultural norms were identified by survey (Yancu et al., 2010).

Traditional African American cultural values about death and dying have been noted to conflict with many areas of the hospice philosophy (Volandes et al., 2007; Washington et al., 2008; Yancu et al., 2010). Many African Americans hold the idea that

decisions about death are to be made by key family members, and that longevity of life is considered good (Ludke, & Smucker, 2007). African Americans report that illness is a family matter that should not be left to outside sources for assistance (Vig et al., 2009). Some African Americans viewed the use of outside healthcare assistance as the family shirking responsibility for the terminally ill member and associated hospice with a lack of hope or poor concern for the ill (Johnson et al., 2008; Enguidanos et al., 2011). African Americans had a more positive perception of life prolonging regression ratios of 2.3:1.4; $p < .0001$ (Barnato et al., 2009). It was reported that decisions being made about death without family input were viewed as a sign of disrespect, or neglect in the duty to care for a loved one (Johnson et al., 2008). In hospice the decision to elect service is made by the patient, Power of Attorney, guardian or closest relative. Yancu et al. identified that there was a poor understanding of African American choices about end of life care decisions. Poor understanding of physicians and hospice workers on the need to have more family involvement in the decision making for hospice have also added to the underutilization of hospice by African Americans (Haas et al., 2007; Yancu et al., 2010). Views of life are impacted by culture and in many instances they are impacted by religious beliefs as well.

The explanation of culture has been used as a catch all for any possible reasons for African American decisions to not use hospice, which does not fall into one of the common barriers of poor knowledge of hospice, access to hospice care, lack of trust in the healthcare system, low rates of minority professional representation, or religion. There were no literature found that clearly defined or measured the impact of culture on hospice use, although it was often cited as a barrier to utilization.

Religiosity

In the African American community, religion has always been a historic mainstay. The early churches have been a source of teaching solidarity, spiritual birth, and renewal (Isaac, Rowland, Blackwell, 2007; Lewis, 2008). Various researchers have constructed many tools in the attempt of measuring levels of spirituality (Lee, Sharpe, 2007). Religiosity encompasses the spiritual perceptions, beliefs, life lessons, and ideology of each individual. 70% of African Americans have professed to be religious, while 86% of that 70% profess to be of the Christian faith (Austin, Harris, 2011). Religiosity has shown to increase as African Americans age (Quinn, Guion, 2010; Raghavan, Smith, Arnold, 2009). African Americans have also been identified to be more involved with their religious entity, as compared to Caucasian Americans (Brown, & Adamczyk, 2009).

Hospice holds a holistic view of its care to meet the physical, psychosocial, and spiritual needs of each patient. In recent years, the church has been used as a hub for healthcare education (Brown, & Adamczyk, 2009; Isaac et al., 2007; Quinn, & Guion, 2010). Although religion has been cited as a barrier to hospice use, there were no data found during the literature review that showed a significant correlation between religion and hospice use. During times of slavery and early establishment of the United States as a country, religion was the core of the African American community. African Americans put trust in religious ideology for deliverance and safe keeping (Isaac et al., 2007; Lewis, 2007). Terminal diagnoses haves often a challenge for patients and family members to

adjust to. There is also the potential of emotional, social, and spiritual conflict that arise with a terminal diagnosis (Quinn, & Guion, 2010).

African Americans were noted to be more likely than Caucasians to identify themselves as religious (Austin, & Harris, 2011). 70% of African Americans also reported church attendance for an undisclosed length of time, or frequency (2011). In a survey where twice as many Caucasians (n = 264) were interviewed as African Americans (n = 115), 54% of Caucasian Americans and 69% of African Americans reported that God was seen as a source of help (Lee, Sharp, 2007). Religiosity was determined to impact hospice use and was not identified to be the same as church attendance. It has been perceived that hope also plays a part in religious convictions. While accepting hospice and stopping any form of aggressive treatment represents a decline in spiritual faith, and also translates as the person attempting to play God (Washington et al., 2008). Some African Americans have also held the ideology that suffering is a part of their spiritual connection to dying (Quinn, & Guion, 2010). African Americans that have religious viewpoints have used scripture in the past to identify suffering as a part of their religious duty. African Americans have also used their religious faith in God to justify aggressive therapies (Brown, & Adamczyk, 2009). African American profession of religion, and request for curative treatment at the end of life has created reluctance on the part of physicians to discuss death and dying options of hospice (Ache et al., 2011).

Religion and Hospice

Religion has been an important component of African American culture and has been identified as a key factor for African American health education, and self-efficacy efforts (Quinn, & Guion, 2010). For this reason hospice was thought to be an appealing benefit for African American patient/family support and spiritual guidance (Ache et al., 2011). Religious and spiritual support was also cited by physicians as a reason for patient referral to hospice services (Ache et al., 2011). Although spiritual support is a mandatory required discipline of hospice, African Americans continue to be less likely to use hospice services (NHPCO, 2010). Religious support has also been cited as the reason most physicians refer patients to hospice care (Ache et al., 2011). However, reluctance of physicians to make hospice referrals based on their opinion of patient religiosity has also been as a barrier to hospice use (Ache et al., 2011).

Strengths of Current Studies

The studies reviewed documented lower rates of hospice participation by African Americans, and identified the barriers to hospice use. These studies were conducted in varying areas of the United States, and were noted to have the same key issues identified as barriers to hospice utilization for African Americans and other minorities. There were also representation of patients, family members, caregivers, hospice employees, and physicians. This also assisted in validating that all points of view had been represented. The information provided from the previous studies confirmed the gaps in information. There was also the unclear and incomplete information that would make it difficult to duplicate some of these studies, because some researchers did not disclose full study

details. I did not complete any type of study to validate that the literature's information was accurate. Quinn and Guion (2010) reviewed previous studies in order to determine religious significance without conducting any study to validate the data that was presented. Washington et al. (2008) reviewed articles and used the presented information in previous articles to address hospice underuse.

The literature reviewed included both qualitative and quantitative methods. Six articles specifically focused on the African American church and its impact on the African American community, the accuracy of religious measurement for African Americans, common belief practices of African Americans, and mistrust of healthcare providers (Austin, & Harris, 2011; Kennedy et al., 2007; Lewis, 2008; Washington et al., 2008). The results identified that African American churches played a role in healthcare. It was also noted that religious practices, such as church attendance, can add quality to life.

Quantitative, qualitative, cross-sectional, and retrospective analysis were used in other studies to identify why African Americans were using hospice less than Caucasian Americans; to explore the availability of Hospice, assess the feasibility of a financial need based criteria, look at race and the impacts of health, and review distrust of healthcare providers (Armstrong et al., 2007; Connor et al., 2008; Haas et al., 2007; Johnson et al., 2011). The findings of these studies identified no specific pattern to distrust of healthcare among African Americans. Studies also identified that more research was needed on the effects of culture, religion, and the decision to use hospice services.

The remaining literature consisted of cross-sectional studies, case studies, focus groups, and surveys that identified barriers to hospice use and how to promote hospice for those who underuse the services. Each of these studies recommended that African Americans should always be asked about their religious beliefs, and suggested that more research be conducted over their decision making process for hospice (Chilton et al., 2008; Johnson et al., 2009; Lee, & Sharpe, 2007; Yancu et al., 2010). According to Austin et al. (2011), religious beliefs should be asked, in order to help enhance the understanding of hospice services, and to best address care from the perspective that is most important to the patient.

Weaknesses of Current Studies

The literature presented on hospice use rates by African Americans contained generalized explanations. The vague interpretations have resulted in little progress being made in improving African American use of hospice. There were also minimal knowledge of associations between the barriers. In all of the studies reviewed there were no evidence of barrier subgroup analyses. There was a lack of information on hospice decision by African Americans based on religious status, age, education, financial status, and demographic location. Because there is no reported review of these barrier subgroups, it has resulted in no documented statistical impact on use of hospice by African Americans. The generalized approach to barriers of trust, knowledge, access, and religiosity has resulted in incomplete information. Even with increased health education that has been used to convey information, the use of hospice services by African Americans continues to be low (Enguidanos et al., 2011).

Although there has been a slight increase in hospice use, African American hospice use has not increased at a rate similar to Caucasian rates (Johnson et al., 2011). As a result of information obtained from previous studies; it is important to understand why African American rates lag behind those of Caucasians despite increased educational efforts by hospice providers (Connor et al., 2008; Johnson et al., 2011). The literature also identified a need to increase hospice knowledge among the African American community to assist in increasing African American use of hospice. There was no information on the importance of religion or the percentage of patients that include religion into their decision for hospice services.

The lack of access to hospice services, uncertainty about end of life intentions, culture, and religion were reviewed consecutively but independent of one another in previously constructed studies about African Americans and hospice. There were no identified correlations. The barriers were then clumped together without in depth analysis of the impact of these barriers, or the intended use of hospice. Religiosity was mentioned several times, but the significance was never explored. Religiosity is a significant component because its teaching embodies all of the barriers associated with African American underuse of hospice. Religiosity deals with positioning to seek for increased knowledge and understanding, trust, service, and spirituality.

Alternative views to the position of religiosity addressed the perspective that decisions are based on knowledge, and that religiosity does not impact decision making. Authors have also cited that African Americans are less likely to use hospice due to personal desires for life sustaining measures at all stages of life. Decisions for life

sustaining measures have promoted the idea that religion is a practice that does not impact the personal choices, or decisions of African Americans. As stated earlier in this chapter, under this perspective religiosity is a learned response that supports socialization and does not change the core philosophies of a person (Brown, & Adamczyk, 2009; Quinn, & Guion 2010). There is no identification of the extent to which religion affects the decision to use hospice.

Summary

This chapter has discussed the underuse of hospice by African Americans. The use of hospice services has been addressed in many fashions of community education, and health initiatives, without a noted change in use. The barriers identified that have impacted the use of hospice services are poor knowledge about hospice, access to hospice, lack of trust, culture, and religiosity. When all of the barriers are considered there is still a noticeable deficit in measuring the extent to which these factors can be used to predict hospice use by African Americans.

Many African Americans are not accepting of end of life palliative care. This has created reluctance on the part of physicians to discuss death and dying options of hospice, with African Americans. There is also the concern that the information shared with African Americans about hospice services does not appeal to or provide answers to the questions that seem to be at the heart of most African American concerns or religious convictions. The disconnection that has existed between the health care professional and the African American community has also impacted the hospice use rate negatively. Chapter 3 will discuss the methodology that will be used to examine the role of

religiosity in intentions of hospice use, and identify any correlation of reported barriers from earlier studies. This study has been based on the barriers identified, related to African American underuse of hospice in the literature review.

Chapter 3: Research Method

Introduction

In this chapter, a discussion of the study design, sampling plan, recruitment strategies, data collection procedures, and analysis is presented. I also describe the methodology that was used for this study and the threats to validity. This chapter ends with a discussion of the protection of human subjects.

There has continued to be low representation of African Americans using hospice services. The primary intent of this study was to identify the association between religiosity (independent variable) and intended hospice use (dependent variable) and to identify the extent to which perception of hospice (mediator) impacts the independent and dependent variables. I also used this study to evaluate whether perceptions of hospice mediate the relationship between religiosity and intention to use hospice among this population.

Research Design and Rationale

The proposed study used a quantitative cross-sectional survey design. A cross-sectional design was used because of the ability to determine association, and it allowed for generalization of a population without follow up being required. This design was selected in order to maintain confidentiality and accessibility. Participants completed an online survey. According to Creswell (2009), quantitative data are numerical measurements that assess the reliability and validity of theories in an unbiased manner. Previous studies examining hospice use among African Americans used focus groups to examine the effects of using culture-specific brochures to sway African Americans to use

hospice (Enguidanos et al., 2011). Very few quantitative studies have addressed hospice choices for African Americans or the association between perceived barriers to hospice and hospice services use (Van Dussen et al., 2011). Many of the studies have identified barriers without examining them for statistical significance. My purpose for this study was to address gaps in reference to the role of religiosity and African Americans' perception of hospice and the association of intention to use hospice services.

Sample

Research has indicated that African Americans are reluctant to participate in research (Johnson et al., 2008). In addition, end of life care and hospice use are sensitive topics that may increase reluctance for this group. A nonprobability convenience sampling strategy was the best fit for this study because it allowed me to more easily recruit the required number of participants. All completed surveys submitted by African American adults at least 18 years of age were included in the sample. I only excluded incomplete surveys and those that were not completed by African Americans age 18 and older.

Sample Size Calculation

I recruited African American adults age 18 and older to participate in the survey. The desired sample size was 146 based on an a priori sample size calculation for multiple linear regression using G* Power 3.1.7 (Faul et al., 2007). In this study, I used convenience sampling strategies to gather data on the association of African American perception of hospice, religiosity, and intent to use hospice. The seven covariates

included in the regression analysis as possible confounders were religiosity, perception of hospice, age, sex, marital status, education, and income level.

In Research Question 1, I examined religiosity (independent variable) and perceptions of hospice (dependent variable). I selected power =.80 to lessen the likelihood of a Type I or Type II error (Cohen, 1992). Alpha = .05 was selected to increase the likelihood of statistical significance. A small effect size = .1 was selected in order to increase prevalence of results, related to the expectation that few respondents would associate level of religiosity and their perception of hospice. Based on G*Power 3.1.7, the sample size was 146 (Faul et al., 2007). Variables of age, sex, marital status, education, and income were included as possible confounders in the analysis.

To answer Research Question 2, I used an a priori sample calculation for multiple linear regression with alpha =.05 based on standard assumptions to identify intent to use hospice (DV) and perceptions of hospice (IV; Cohen, 1992). A small ES of .80 was used related to expectations that few respondents would indicate intent to use hospice (Johnson et al., 2008; Johnson et al., 2009). A power of .80 was used to increase result significance. ES = .1, alpha = .05, power = .80 yielded a minimal sample size of 146. Covariates of age, sex, marital status, education, and income were also included in this model as possible confounders.

Research Question 3 was answered using a small ES = .10 to increase the viability of the effect, based on assumptions that few respondents would be willing to share information about their level of religiosity. According to Cohen (1992), a small effect size will increase the sample for the detection of prevalence. Alpha reliability for

religiousness measures have been considered acceptable at a rate of .72 (Johnson et al., 2009). It was believed that the level of participants that would report plans to use hospice would be low. Standard alpha = .05 was assessed to indicate that any relationship identified between religiosity and intent to use hospice was a true assessment and not due to chance. A power of .80 was used to analyze the correlation of religiosity (IV) and intent to use hospice (DV), in order to decrease the risk of a Type I or Type II error (Cohen, 1992). Based on G*Power 3.1.7, the sample size identified was 146. Variables of age, sex, marital status, education, and income were also assessed as possible confounders.

In Research Question 4, I used a priori sample calculation with alpha = .05, power = .80, ES = .1 based on standard assumptions (Cohen, 1992). The power of .80 was selected to increase the ability to identify significant findings. According to Johnson et al. (2008), an acceptable reliability rate for religiousness measures is .72. As written previously, it was expected that few participants would report intent to use hospice (DV) and associate levels of religiosity (IV) or perception of hospice (mediator). Based on G*Power 3.1.7, the sample size identified was 146.

In the survey, I also collected information about participants’ age, sex, marital status, education, and income that could confound the relationship among perceptions of hospice (mediator), religiosity (independent variable), and intent to use hospice (dependent variable). This analysis was conducted to examine the independent variable, dependent variable, and mediator. I was also controlling for age, sex, marital status, education, and income.

There were no studies found that reported the percentage of African Americans who intend to use hospice. Current rates of hospice use indicate that use among African Americans is low (NHPCO, 2010; Washington et al., 2008). A small ES was used in the sample size calculation to reflect the relatively low rates of African Americans who choose to use hospice. It was anticipated that the rates of intention to use hospice observed in this study would be higher than recent estimates of actual hospice use. The small ES of .10 was selected using Cohen's standard values to increase the observed sample size (Cohen, 1992).

The statistical power used to determine the required sample was .80 based on standard assumptions. The statistical power was chosen in order to keep the sample size feasible for completion of the study and to increase the ability of the study to determine whether religiosity is associated with intent to use hospice or mediated by perceptions of hospice (Cohen, 1992). Alpha has been identified as .05 in reference to the standards that would prevent premature rejection of the null hypothesis (Cohen, 1992). Using the sample size parameters was beneficial in relation to looking at intention and not actual use of hospice by African Americans. The sample size calculations above indicated that a total sample of 146 would be sufficient to adequately assess whether there was a difference in intention to use hospice based on religiosity or based on perceptions of hospice. In addition, this sample size allowed me to determine whether or not any association between religiosity and intention to use hospice was mediated by perceptions of hospice.

Procedures for Recruitment

Study recruitment was conducted in coordination with the National Oklahoma City Douglass High School Alumni Association (NOCDHSAA), which allowed me to distribute recruitment information to members via the organization's website (Appendix D). This alumni association is affiliated with a predominantly African American high school that has been known in the Oklahoma City community to have a very active alumni participation level. NOCDHSAA connects with African Americans of varying professional, educational, and economic status. Recruitment did not focus on one particular location, due to members of NOCDHSAA residing in different regions of the United States. Responses were excluded from the sample if participants were not African American, were not at least 18 years old, or did not complete the entire survey.

Data Collection Procedures

After approval from Walden University's IRB (Approval # 05-23-14-0119206), the letter of invitation was forwarded to National Oklahoma City Douglass High School Alumni Association. The letter of invitation included an explanation of the survey, consent, and instructions to complete and submit the survey (Appendix E). The letter of invitation was also posted to the alumni website (www.douglasstrojans.ning.com) so that members would be provided a survey description, consent information, and details on how to access and complete the survey. The surveys were self-administered using Survey Monkey, an online program used for data collection. This provided increased privacy and prompt return of the surveys. It also provided easy access and prompt thorough completion of the survey. I was able to retrieve data after the survey was submitted by a

participant. It was estimated that it would take each participant no more than 20 minutes to complete the entire survey. Participants did not receive incentives for completing the survey. Participant informed consent did not require a signature but did explain that clicking the link to complete the survey would signify consent (Appendix J). The survey website (www.douglasstrojans.ning.com) remained active for a 2-month period.

Instrumentation

The AARP EOL Survey (Appendix F) was used to assess the aspects of end of life care choices of African American participants, with permission from the AARP (Appendix A). The instrument was used to examine EOL views and choices. The AARP survey was previously used and validated in North Carolina for a study with people aged 55 and older with a reported sampling error of +/- 1.7% (AARP; Straw, & Cummins, 2003). Reliability was established based on coefficient alpha = .81. In this study, all adult ages were included in the sample. This instrument was selected because it contains questions that address end of life care preferences, and beliefs about dying and religiosity.

Intent to use hospice was determined based on the response to Question 7 of the AARP EOL Care Survey (Appendix F; "If you were dying would you want hospice support?"). A positive response served as an indication of intent for this study. The response was scored (2 = *yes*, 1 = *don't know/not sure*, 0 = *no*). The findings examined changes in the outcome variable (intention) as the independent variable (religiosity) changed, using multiple linear regression.

Perception of hospice was also based on the responses to Questions 6, 8, 10, 11, and 12 provided in the Hospice Perception survey (Appendix H). The questions allowed the participants to answer based on their view of hospice (e.g., use of hospice is seen as giving up). The responses were quantified using a 4-point Likert-type scale with lower scores indicating a positive perception of hospice. A sum of all responses were calculated and a mean score identified to rate participant perception.

There was one reported process attempt to validate the Perception of Hospice survey tool (Van Dussen et al., 2011). This survey involved measurement of frequencies, bivariate analysis, and descriptive statistics (Van Dussen et al., 2011). This study looked at knowledge of hospice attitude and perception of hospice of people age 43 and older. Prior to sample recruitment, a focus group was conducted with hospice staff and volunteers of a hospice company. The purpose of the focus group was to determine the length of time needed for survey completion and to gather feedback on the clarity of the questions. No changes to the study were made after the focus group. This initial pilot study was to be a prelude to a larger study. The pilot study was determined to have limited success, related to the difficulty of getting referred participants from local churches to complete the survey (Van Dussen et al., 2011). The survey tool was considered reliable in the measurement of hospice perception and knowledge (Spearman’s rho = -.17, $p = .033$; Van Dussen et al., 2011). Many who refused to participate in the study were in the proposed target group.

The religiousness measure (Appendix G) quantified the level of reported religiosity by addressing religious perspective and individual spirituality. This tool

focused on and assessed religious influence. Answers to this portion of the survey were scored using mean scoring. This survey was developed and used by Sethi and Seligman (1993). The initial purpose of this tool was to identify any correlations of religiosity with style and level of hope while measuring influence, practice, and affiliation. There was one reported process attempt to validate the Religiousness Measure with other religious scales. Sethi and Seligman (1994) found significant correlations that supported the religious classifications, establishing reliability scores for each subscale (with religious involvement $r = .08$, religious influence $r = 14$, and religious hope $r = .21$). Two subscales of this survey, religious involvement and religious influence, were used to score religiosity.

Religiosity was measured to identify the correlation of levels of religiousness with intention to use hospice. This portion of the study also addressed reported level of religious practice and affiliation by participants in Questions 10-12 (e.g., “How often do you attend religious services and activities?”). Religious influence was measured using Questions 13-17 (e.g., “How much influence do your religious beliefs have on the important decisions of your life?”). The religiousness measure survey questions were scored based on the sum of all questions to categorize participant level of religiosity. Religious influence was scored on a 7-point Likert-type scale, with 7 indicating a high level of religious affiliation (Questions 10-12). Religious influence (Questions 13-17) was scored on a 6-point Likert-type scale, with 6 indicating a high level of influence (Sethi, & Seligman, 1993). These scores, using mean scoring, were then combined to identify the overall participant level of religiosity.

The final participant survey combined the AARP EOL care survey (2003), religiousness measure survey (1993), and the perception of hospice survey (2011). It also included questions that addressed demographic characteristics of the study sample (Appendix I). Participants' race, age group, sex, marital status, education level, and income were assessed to assist in identifying any trends or correlations of responses that were consistent within specific subgroups of the study sample.

A pilot study was conducted to determine the reliability and validity of the newly created instrument. A pilot study was needed in order to ensure that questions were appropriate for all adult ages, because the AAARP survey was administered to adults age 55 and older only (Straw, & Cummins, 2003). The perception of hospice survey tool also was conducted with adults who were age 43 and older (Van Dussen et al., 2011). In addition, the survey instrument was a combination of three tools that had not previously been used together. For the pilot study, 16 participants (approximately 10% of the required sample) completed the participant survey. The results of the pilot study were assessed for validity and reliability to determine whether changes needed to be made to the survey instrument before data analysis began.

Data Analysis

Data were collected using the online survey. The questionnaire used the Likert-type scale to measure responses for the continuous variables: religiosity, use of hospice services, and African American perception of hospice. Descriptive mean and standard deviation of the survey results were calculated. Multiple regression analysis was conducted using Statistical Package for the Social Sciences (SPSS) 21.0 to measure the

association between (a) religiousness on African American end of life care decisions, and (b) perceptions of hospice use, and (c) intention to use hospice.

Research Question 1 was assessed using Questions 6, 8, 10, 11, and 12 of the Perception of hospice survey (Table 1). Perception was used as the outcome variable. The religiosity variable was constructed as previously described. Variables of religiosity, age, sex, marital status, education, and income were included as independent variables in a multiple regression. These variables were included in the model as possible confounders, in order to examine the associations between religiosity and perceptions of hospice, while controlling for age, sex, marital status, education, and income.

Intent to use hospice was assessed in Research Question 2 as the outcome variable. Intent was determined by the response provided to Question 7 of the AARP EOL Care survey (Table 1). Perception of Hospice was determined by responses provided to Questions 6, 8, 10, 11, and 12 of the Hospice Perception survey (Appendix H).

To assess Research Question 3, intent to use hospice was defined by the answers provided to Question 7 of the AARP EOL Care survey (Table 1). The response to this item was used as the outcome variable. Religiosity was constructed using Questions 1, 2, 3, 4, 5 and 6 from the Religiousness measure that identified involvement and influence (Sethi & Seligman, 1993). The mean scores for these six items were used to create the religiosity variable (Sethi & Seligman, 1993). The constructed religiosity variable, age, sex, marital status, education, and income were included as independent variables in a multiple regression analysis. The listed variables were included as possible confounders.

Research Question 4 was assessed using Questions 6, 8, 10, 11, and 12 of the Perception of hospice survey (Table 1), Questions 1, 2, 3, 4, 5, and 6 of the Religiousness measure survey tool, and Question 7 of the AAPR EOL Care survey. Intent was used as the outcome variable. The religiosity variable was constructed as previously described. Variables of religiosity, age, sex, marital status, education, and income were included as independent variables in a multiple regression. Perception was constructed as previously described and assessed for correlation of changes with religiosity changes in scores. Covariance was used to explain the relationship of intent to use hospice, perception, and religiosity, by identifying any relationship between variables.

Table 1
Variable Relationship Measures: Religiosity, Perception and Intent to Use Hospice

Research question	Variable of interest	Survey tool	Question #	Statistical test
What is the association between religiosity and perceptions of hospice among African Americans?	Religiosity	Religiousness Measure (Appendix G)	1, 2, 3, 4, 5, 6	Multiple linear regression
	Perception of hospice	Hospice Perception Survey (Appendix H)	6, 8, 10, 11, 12	
	Age Sex Marital status Education Income	Demographic Survey (Appendix I)	3, 4, 5, 6, 7	
What is the association between intent to use hospice and perception of hospice among African Americans?	Intent to use hospice	AARP EOL Care Survey (Appendix F)	7	Multiple linear regression
	Perception of hospice	Hospice Perception Survey (Appendix H)	6, 8, 10, 11, 12	
	Age Sex Marital Status Education Income	Demographic Survey (Appendix I)	3,4,5,6,7	
What is the association between religiosity and the intent to use hospice among African Americans?	Religiosity	Religiousness Measure Survey (Appendix G)	1, 2, 3, 4, 5, 6	Multiple linear regression
	Intent to use hospice	AARP EOL Care Survey (Appendix F)	7	
	Age Sex Marital status Education Income	Demographic Survey (Appendix I)	3, 4, 5, 6, 7	
Do perceptions of hospice mediate the association between African American religiosity and intent to use hospice?	Perception of hospice	Hospice Perception Survey (Appendix H)	6, 8, 10, 11, 12	
	Religiosity	Religiousness Measure Survey (Appendix G)	1, 2, 3, 4, 5, 6	Multiple linear regression
	Intent to use hospice	AARP EOL Care Survey (Appendix F)	7	

Each research question was analyzed to determine the variance of each measure for the dependent variable (intent to use hospice), independent variable (religiosity) and the mediator (perception of hospice). I also calculated the values of each variable for determination of frequency of occurrence, and value. Frequencies determined categorical identification of participants. Perception of hospice was identified as the covariate in the analysis of how much the perception of hospice and level of religiosity change together. In Research Question 1, frequency of occurrence and value were also determined, and cross tabulated to identify any relationship. Covariance was also measured to determine the correlation and statistical significance between intent to use hospice and perceptions of hospice in Research Question 2. In Research Question 3 covariance was also measured to determine relationship between religiosity and intent to use hospice. I analyzed these variables for statistical significance. Descriptive analyses were also used in each research question to provide a summary of all data frequency and proportion.

Threats to Validity

The threat to construct validity referred to generalizable assumptions being made about all African Americans' intent to use hospice, associations of religiosity, and perceptions of hospice related to using convenience sampling. Threats to external validity were that participants may have answered questions according to what was perceived as socially acceptable, as opposed to their views, which could misrepresent and result in inaccurate data. Participants could have also interpreted survey questions differently from my intended meaning. Internal and external threats to validity could have been related to participants having previous positive or negative encounters with hospice.

Internal validity could have been threatened as a result of the participant having a life changing event occur. The event could have affected participants' intent to use hospice. The threats to internal validity could have affected the ability to determine that positive associations observed were accurate or due to the factors observed. The survey being longer than reported could have also been a threat to the experimental mortality of the study. This could have resulted in fewer participants completing the entire survey. The reliability of the dependent variable scores could have also affected the statistical regression of this study.

In order to limit threats to construct validity, acceptable definitions, based on those in the literature, were used to provide explanation of the variables. Each variable was operationalized using scales that have been previously assessed for construct validity. A pilot study was conducted to look at the length of the survey, and the reliability of the independent variable and dependent variable scores. The survey was available to participants via Survey Monkey to ensure that my bias was not a factor. The participant survey was standardized in order to prevent any threats to the instrumentation of this study.

Human Subjects Protections

Informed consent was implied by clicking the survey link. The study was not conducted until Walden IRB approval had been granted. Confidentiality and duplicate entry were ethical concerns. No information that could identify the participants were collected or shared with any other party. Participants were asked to complete only one survey. Because hospice can be a difficult topic of discussion for some, participants were

provided a link to the National Hospice and Palliative Care website (www.nhpco.org) where they could access additional hospice information and local support groups in their areas. Because the survey was being conducted online, there was also the possibility that a participant might be deceptive about meeting criteria of age or race. The electronic consent preceded the survey with explanation of intent, how information would be used and a description of the inclusion criteria. Participants were informed that they may withdraw at any time during the process of completing the survey.

The data collected has been kept in a hard drive that is password protected. The data from Survey monkey were imported and stored in the SPSS program for analysis. Data entered into SPSS were also committed to a password protected folder. I have had access to the private data, by password only.

Summary

Chapter 3 has described the process that was used to implement the quantitative cross sectional study that was used to identify if a correlation between religiosity and hospice use by African Americans exist. The research design, method of recruitment and data collection procedures were presented. In addition, the data analysis procedures and protections of human subjects have been described. Chapter 4 will describe the pilot study results, data collection process of the main study, and provide descriptive and statistical results of the study.

Chapter 4: Data

Introduction

In this chapter, I present the results of a cross sectional quantitative data analysis used to address the research question. Research Question 1 examined the association between religiosity and perception of hospice by African Americans. Research Question 2 examined the association between intent to use hospice and African American perceptions of hospice. The association between religiosity and African American intent to use hospice was reviewed in Research Question 3. Research Question 4 asked if perceptions of hospice mediated the association between African American religiosity and intent to use hospice. The survey results provided descriptive correlational and multiple regression information, addressing variable significance. This chapter includes the results of the pilot study, data collection, data analysis, and a summary of the findings for each research question.

Pilot Study

A pilot study was conducted to determine the reliability and validity of the newly created instrument, in order to ensure that questions were appropriate for all participants regardless of age. The pilot study involved the first 16 surveys (approximately 10%) that were completed in their entirety by African American participants using Survey Monkey. The pilot study was conducted due to three different surveys being used together for participant response for the first time. The surveys were the AARP EOL Care Survey (Appendix F), Hospice Perception Survey (Appendix H), and Religiousness Measure

survey (Appendix G). No problems were identified. As a result, data collection was not interrupted.

No barriers or issues were noted that impeded data collection or affected the ability to collect data from participants. Respondents did not seem to have any difficulty understanding the questions. As a result, there were no changes to the survey instrument. Therefore, the data collection method was not interrupted or changed during the data collection period.

Data Collection

The data collection time frame allotted was 2 months. The data collection occurred for a total of 23 days, after which no more results were received. The desired data collection sample size for this study was determined to be 146 participants based on a priori G*Power 3.1.7. In the instance of this survey, 24 participants responded within the first 48 hours. The highest response rate occurred on Day 2, with a total of 84 responses (this included ineligible responses).

There were a total of 187 survey attempts. This included a total of 15 surveys that were ineligible, due to the participants not self-identifying as African American. Another 18 surveys were incomplete and were excluded from analysis. My original plan allowed 2 months for data collection. After 23 days, there had been a total of 154 eligible surveys completed. During the 23-day time frame, there were some days in which there were no responses to the survey. Data collection was ended on Day 31, after no more survey submissions were received.

There was no deviation from the plan for importation of data. The eligible data were imported from Survey Monkey directly into SPSS. No interventions were conducted, nor did I have interaction with any participants. The responses provided to the surveys were anonymous via Survey Monkey, with no follow-up contact or correspondence with participants. There was also no information collected that could identify any participants.

Participant Characteristics

The sample consisted of African American adults who self-reported to be at least 18 years old or older. The participant ages ranged from 22 to 75 years old, with many between age 30 and 55 (70.8%). The mean age of participants was 41. The majority of participants (25.3%) were married. Participant demographic data have been provided in Table 2. There was no representation of African Americans who had less than a high school diploma in this study, and 48.05% of participants self-reported to have a college degree. There was also representation of all economic fields per the participants' self-reported income.

Table 2

Demographic Frequencies and Percentages

	N	(%)
Sex		
Male	34	22.1
Female	120	77.9
Age		
18-29	25	16.2
30-42	73	47.4
43-55	36	23.4
56-65	15	9.7
65+	5	3.3
Marital status		
Single	37	14.0
NM	20	7.5
Married	67	25.3
LTAM	3	1.1
Separated/Divorced	6	2.3
Widowed	20	7.5
	1	.4
Education		
HS/Equiv.	31	20.13
SC/Tech	49	31.82
College grad	55	35.71
Post grad	19	12.34
Annual income		
< 20k	12	7.8
20K- < 40k	35	22.7
40K- < 60K	30	19.5
60K- < 80K	20	13.0
80K- < 100K	23	14.9
100K+	34	22.1

Note. NM = never married; LTAM = living together as if married; HS/Equiv = high school diploma/equivalent; SC/Tech = some college/ technical training; Grad= graduate.

Results

In this study, 63% of participants surveyed identified strong agreement with hospice being important, while another 10.4% felt that hospice was not at all important. Table 3 presents the distribution of this variable. The analysis identified 84.1% (*n* = 130) of survey participants who self-reported religiosity as extremely important in Question 1 of the Religiousness Measure survey (Appendix G).

Table 3

Descriptive Statistics: Number and Percentage of Hospice Importance

	SA (%) *N*	MA (%) *N*	MD (%) *N*	SD (%) *N*
Important	97 (63.0)	38 (24.7)	3 (1.9)	16 (10.4)
				Total = 154

Note. SA = strongly agree; MA = mildly agree; MD = mildly disagree; SD = strongly disagree; (%) = the percentage of participants who provided the answer in the study. *N* = number of participants.

The religiosity measure includes Questions 1, 2, 3, 4, 5, and 6 of the Religiousness Measure survey (Appendix G). Based on the scoring of the instrument, a mean score for religiosity was calculated. For this sample, the mean religiosity was 5.068 with a standard deviation +/-1.328. The mean score identified for hospice perception was 1.291; SD +/- .476. However, only 75 (48.7%) participants identified that their religious beliefs influenced their decision making in Question 2 of the Religiousness Measure survey (Appendix G).

The perception of hospice variable was based on responses to Questions 6, 8, 10, 11, and 12 of the Hospice Perception Survey (Appendix H). Perception scores were

reviewed based on survey responses to the Hospice Perception Survey (Appendix H). According to survey responses, 67.5% of respondents felt that hospice was expensive, 87.7% felt that hospice was important, and 95.5% viewed hospice as being a valuable service. Only 19.5% felt that hospice was giving up. Percentages of responses are presented in Table 4.

Table 4

Descriptive Perception of Hospice Number, Percentage

	SA (%) *N*	MA (%) *N*	MD (%) *N*	SD (%) *N*
Expensive	33(21.4)	71(46.1)	29(18.8)	21(13.6)
Valuable service	109(70.8)	38(24.7)	2(1.31)	5(3.2)
Giving up	6(3.9)	24(15.6)	51(33.1)	73(47.4)
Equals death	11(7.1)	40(26)	40(26)	63(40.9)
Important	97(63)	38(24.7)	3(1.9)	16(10.4)
				Total = 154

Note. SA = strongly agree; MA = mildly agree; MD = mildly disagree; SD = strongly disagree; (%) = the percentage of participants who provided the answer in the study. *N* = number of participants.

The intent to use hospice was based on responses to Question 7 of the AARP End of Life Care Survey (Appendix F). Among participants, 51.9% reported a positive intent to use hospice services (Table 5), and 6.5% reported that they would not use hospice. Another 41.6% of the participants were unable to positively or negatively identify their choice to use hospice.

Table 5

Intent to Use Hospice Demographics (N = 154)

	Yes *N* (%)	No *N* (%)	Unsure *N* (%)	No response *N* (%)
Intent to use hospice	80 (51.9)	8 (5%)	64 (41.6)	2 (1.3)

The mean scores for the variables of interest are presented in Table 6.

Table 6

Religiosity, Perception of Hospice, and Intent Descriptive Mean, Standard Deviation

	Mean	Std. deviation	*N*
Perception	1.291	.4764	154
Religiosity	5.068	1.328	154
Intent	1.91	.986	154

Research Question 1

Research Question 1 (RQ1): What is the association between religiosity and perceptions of hospice among African Americans?

- $H1_0$: There is no association between religiosity and African American perceptions of hospice.
- $H1_1$: There is an association between religiosity and African American perceptions of hospice.

To assess the association between religiosity and perception of hospice, a Pearson correlation was calculated. The results of the correlation analysis are presented in Table 7. Religiosity was found to be significantly associated with perceptions of hospice (r = .167; p = .038). The correlation analysis also indicated that age was significantly associated with religiosity (r = .240; p = .003). While the additional independent

variables of education, income, and marital status were not significantly associated with religiosity, they were retained for the regression model, as previous research has indicated that they may be associated with perceptions of hospice.

Table 7

Correlation of Religiosity, Perception of Hospice, Age, Sex, Marital Status, Education, Income

		Religiosity	Perception	Age	Sex	Marital status	Income	Educ
Religiosity	Pearson correlation	1	.167*	.240**	.004	-.036	-.022	-.130
	Sig. (2-tailed)		.038	.003	.964	.656	.789	.107
	N	154	154	154	154	154	154	154
Perception	Pearson correlation	.167*	1	.026	.062	-.060	-.021	.089
	Sig. (2-tailed)	.038		.749	.442	.456	.799	.270
	N	154	154	154	154	154	154	154
Age	Pearson correlation	.240**	.026	1	-.037	.383**	.154	-.055
	Sig. (2-tailed)	.003	.749		.652	.000	.056	.495
	N	154	154	154	154	154	154	154
Sex	Pearson correlation	.004	.062	-.037	1	-.013	-.094	-.055
	Sig. (2-tailed)	.964	.442	.652		.874	.247	.498
	N	154	154	154	154	154	154	154
Marital status	Pearson correlation	-.036	-.060	.383**	-.013	1	.036	.108
	Sig. (2-tailed)	.656	.456	.000	.874		.658	.181
	N	154	154	154	154	154	154	154
Income	Pearson correlation	-.022	-.021	.154	-.094	.036	1	.034
	Sig. (2-tailed)	.789	.799	.056	.247	.658		.678
	N	154	154	154	154	154	154	154
Education	Pearson correlation	-.130	.089	-.055	-.055	.108	.034	1
	Sig. (2-tailed)	.107	.270	.495	.498	.181	.678	
	N	154	154	154	154	154	154	155

*Correlation is significant at the 0.05 level (2-tailed). **Correlation is significant at the 0.01 level (2-tailed).

A multiple linear regression was performed where the hospice perception score was used as the dependent variable and the religiosity score was used as the independent variable, in order to further address RQ 1. The multiple linear regression indicated poor model fit (*R* = .224; *p* = .594; Table 8). This indicates that the IV does not account for much of the observed variance in perception of hospice.

Table 8

Regression Analysis of Religiosity and Perception of Hospice

Model	*R*	*R* square	Adjusted *R* square	Std. error of the estimate	*p*
1	.224a	.050	.011	.474	.594

Results of the multiple linear regression indicate that there is a significant relationship between religiosity and perception of hospice (*B* = .174, *p* = .041) when controlling for age, sex, marital status, and income. None of the other variables were found to be significantly associated with perceptions of hospice. The results of the regression analysis are presented in Table 9. For Research Question 1, I rejected the null hypothesis.

Table 9

Regression of Religiosity, Perception of Hospice, Age, Sex, Marital Status, Education

Model		Unstandardized coefficients		Standardized coefficients	*t*	Sig.
		B	Std. error	Beta		
1	(Constant)	.725	.294		2.470	.015
	Religiosity	.062	.030	.174	2.066	.041
	Age	.001	.004	.025	.273	.785
	Sex	.077	.093	.067	.829	.408
	Marital status	-.023	.026	-.076	-.857	.393
	Income	-.005	.023	-.016	-.195	.846
	Education	.063	.041	.126	1.537	.126

Note. Constant; religiosity, age, sex, marital status, income, education.

Research Question 2

Research Question 2 (RQ2): What is the association between intent to use hospice and perceptions of hospice among African Americans?

- $H2_o$: There is no association between intent to use hospice and perception of hospice.
- $H2_1$: There is an association between intent to use hospice and perception of hospice.

To address the association between intent to use hospice and African American perception of hospice, Pearson correlation was calculated. The results of the correlation analysis are presented in Table 10. The results of perception of hospice and intent to use hospice are negatively correlated ($r = -.205$; $p = .011$). The intent to use hospice scores (Appendix F) was lower for those with higher perception of hospice scores (Appendix H). In scoring, a response of yes to intent to use hospice was equivalent to 1. Negative correlations included participant age and intent to use hospice ($r = -.236$; $p = .003$). The result identifies that the younger the participant, the less favorable the perception of hospice.

Table 10

Correlation of Intent to Use Hospice, Perception of Hospice, Age, Sex, Marital Status, Income, Education

		Perception	Intent = Hospice	Age	Sex	Marital status	Income	Education
Perception	Pearson Correlation	1	-.205*	.026	.062	-.060	-.021	.089
	Sig. (2-tailed)		.011	.749	.442	.456	.799	.270
	N	154	154	154	154	154	154	154
Intent= Hospice	Pearson Correlation	-.205*	1	-.236**	-.129	-.006	-.088	-.038
	Sig. (2-tailed)	.011		.003	.111	.944	.278	.644
	N	154	154	154	154	154	154	154
Age	Pearson Correlation	.026	-.236**	1	-.037	.383**	.154	-.055
	Sig. (2-tailed)	.749	.003		.652	.000	.056	.495
	N	154	154	154	154	154	154	154
Sex	Pearson Correlation	.062	-.129	-.037	1	-.013	-.094	-.055
	Sig. (2-tailed)	.442	.111	.652		.874	.247	.498
	N	154	154	154	154	154	154	154
Marital Status	Pearson Correlation	-.060	-.006	.383**	-.013	1	.036	.108
	Sig. (2-tailed)	.456	.944	.000	.874		.658	.181
	N	154	154	154	154	154	154	154
Income	Pearson Correlation	-.021	-.088	.154	-.094	.036	1	.034
	Sig. (2-tailed)	.799	.278	.056	.247	.658		.678
	N	154	154	154	154	154	154	154
Education	Pearson Correlation	.089	-.038	-.055	-.055	.108	.034	1
	Sig. (2-tailed)	.270	.644	.495	.498	.181	.678	
	N	154	154	154	154	154	154	155

*Correlation is significant at the 0.05 level (2-tailed). **Correlation is significant at the 0.01 level (2-tailed).

A multiple linear regression was performed where intent to use hospice was used as the dependent variable and the hospice perception score was used as the independent variable, in order to further address RSQ 2. The multiple linear regression indicated a poor model fit and did not thoroughly describe or capture the factors that impact the decisions to use hospice services (R = .352; p = .393; Table 11).

Table 11

Regression Analysis of Intent to Use Hospice and Perception of Hospice

Model	*R*	*R* square	Adjusted *R* square	Std. error of the estimate	*p*
1	.352a	.124	.088	.941	.393

Results of the multiple linear regression indicate that the relationship between perception and intent to use hospice is statistically significant ($B = -.181$, $p = .002$) when controlling for age, sex, marital status, income and education (Table 12). Based on these results the null hypothesis was rejected for Research Question 2.

Table 12

Regression of Perception and Intent to Use Hospice

Model		Unstandardized coefficients		Standardized coefficients	*t*	Sig.	95.0% confidence interval for B	
		B	Std. error	Beta			Lower bound	Upper bound
1	(Constant)	4.008	.543		7.382	.000	2.935	5.081
	Perception	-.374	.162	-.181	-2.317	.022	-.694	-.055
	Age	-.023	.007	-.264	-3.097	.002	-.037	-.008
	Sex	-.320	.184	-.135	-1.735	.085	-.684	.045
	Marital status	.056	.052	.091	1.071	.286	-.047	.160
	Income	-.039	.047	-.065	-.829	.408	-.131	.053
	Education	-.053	.082	-.051	-.649	.517	-.215	.109

Note. Constant, perception, age, sex, marital status, income, education.

Research Question 3

Research Question 3 (RQ3): What is the association between religiosity and the intent to use hospice among African Americans?

- $H3_o$: There is no association between religiosity and African American intent to use hospice.

- $H3_1$: There is an association between religiosity and African American intent to use hospice.

To assess the association between religiosity and intent to use hospice a Pearson correlation was calculated. The result of the correlation analysis are presented in Table 13. A possible correlation was noted in religiosity, sex, marital status, and age. There was a significant correlation noted between religiosity and intent to use hospice. In addition, age and religiosity were positively associated. As participant age increased, reported level of religiosity increased. There was a negative correlation noted between intent and age ($r = -.236$, $p = .003$; Table 13). While the additional independent variables, education, and income were not significantly associated with religiosity; they were retained for the regression model as previous research has indicated that they may be associated with religiosity.

Table 13

Correlation of Religiosity, Intent to Use Hospice, Age, Sex, Marital Status, Income, and Education

		Age	Sex	Marital Status	Income	Educ	Relig	Intent= Hospice
Age	Pearson Correlation	1	-.037	.383**	.154	-.055	.240**	-.236**
	Sig. (2-tailed)		.652	.000	.056	.495	.003	.003
	Sum of Squares and Cross-products	19920.214	-26.571	1068.071	448.214	-91.429	557.523	-407.000
	Covariance	130.197	-.174	6.981	2.930	-.598	3.644	-2.660
	N	154	154	154	154	154	154	154
Sex	Pearson Correlation	-.037	1	-.013	-.094	-.055	.004	-.129
	Sig. (2-tailed)	.652		.874	.247	.498	.964	.111
	Sum of Squares and Cross-products	-26.571	26.494	-1.312	-9.935	-3.312	.308	-8.091
	Covariance	-.174	.173	-.009	-.065	-.022	.002	-.053
	N	154	154	154	154	154	154	154
Marital Status	Pearson Correlation	.383**	-.013	1	.036	.108	-.036	-.006
	Sig. (2-tailed)	.000	.874		.658	.181	.656	.944
	Sum of Squares and Cross-products	1068.071	-1.312	389.539	14.617	25.039	-11.739	-1.364
	Covariance	6.981	-.009	2.546	.096	.164	-.077	-.009
	N	154	154	154	154	154	154	154
Income	Pearson Correlation	.154	-.094	.036	1	.034	-.022	-.088
	Sig. (2-tailed)	.056	.247	.658		.678	.789	.278
	Sum of Squares and Cross-products	448.214	-9.935	14.617	423.851	8.117	-7.352	-22.091
	Covariance	2.930	-.065	.096	2.770	.053	-.048	-.144
	N	154	154	154	154	154	154	154

		Age	Sex	Marital Status	Income	educ	Relig	Intent= Hospice
Education	Pearson Correlation	-.055	-.055	.108	.034	1	-.130	-.038
	Sig. (2-tailed)	.495	.498	.181	.678		.107	.644
	Sum of Squares and Cross-products	-91.429	-3.312	25.039	8.117	50702.877	-25.095	-5.364
	Covariance	-.598	-.022	.164	.053	329.239	-.164	-.035
	N	154	154	154	154	155	154	154
Religiosity	Pearson Correlation	.240**	.004	-.036	-.022	-.130	1	-.078
	Sig. (2-tailed)	.003	.964	.656	.789	.107		.335
	Sum of Squares and Cross-products	557.523	.308	-11.739	-7.352	-25.095	269.864	-15.676
	Covariance	3.644	.002	-.077	-.048	-.164	1.764	-.102
	N	154	154	154	154	154	154	154
Intent= Hospice	Pearson Correlation	-.236**	-.129	-.006	-.088	-.038	-.078	1
	Sig. (2-tailed)	.003	.111	.944	.278	.644	.335	
	Sum of Squares and Cross-products	-407.000	-8.091	-1.364	-22.091	-5.364	-15.676	148.727
	Covariance	-2.660	-.053	-.009	-.144	-.035	-.102	.972
	N	154	154	154	154	154	154	154

**Correlation is significant at the 0.01 level (2-tailed).

A multiple linear regression was performed where intent to use hospice was assessed as the dependent variable and the religiosity score was used as the independent variable, in order to further address RSQ 3. The multiple linear regression indicated poor model fit and did not completely account for or explain factors that have an impact on intent to use hospice (R=.078; p = .950; Table 14).

Table 14

Regression Analysis of Religiosity and Intent to Use Hospice

Model	R	R square	Adjusted R square	Std. error of the estimate	p
1	.078a	.006	.000	.986	.950

After controlling for the effects of age, sex, marital status, income and education, religiosity was not a significant predictor of intention to use hospice (B = -.019, p = .816). I rejected the null hypothesis for research question 3. The results of this analysis are presented in Table 15.

Table 15

Regression of Religiosity and Intent to Use Hospice

Model		Unstandardized coefficients		Standardized coefficients	t	Sig.	95.0% confidence interval for B	
		B	Std. error	Beta			Lower bound	Upper bound
1	(Constant)	3.695	.594		6.220	.000	2.521	4.869
	Age	-.024	.008	-.273	-3.027	.003	-.039	-.008
	Sex	-.349	.187	-.147	-1.862	.065	-.719	.021
	Marital status	.066	.054	.106	1.226	.222	-.040	.172
	Income	-.036	.047	-.062	-.768	.443	-.130	.057
	Education	-.076	.083	-.073	-.908	.366	-.241	.089
	Religiosity	-.014	.061	-.019	-.232	.816	-.135	.107

Research Question 4

Research Question 4 (RQ4): Do perceptions of hospice mediate the association between African American religiosity and intent to use hospice?

- $H4_1$: Perceptions of hospice do not mediate the association between religiosity and intent to use hospice.
- $H4_2$: Perceptions of hospice mediate the association between religiosity and intent to use hospice.

The responses of 154 participants were analyzed to assess if the perception of hospice mediates the association between religiosity and intent to use hospice. To assess the mediated association a Pearson correlation was calculated. The results of the correlation analysis are presented in Table 16. Religiosity was found to be significantly associated with perceptions of hospice (r = .167; p = .038; Table 16). Perception of hospice scores did not show a significant causal relationship between religiosity and intent to utilize hospice services. There was a significant negative relationship noted between intent to use hospice and African American perception of hospice (r = -.205; p = .011; Table 16).

Table 16

Correlation of Religiosity, Perception of Hospice, and Intent to Use Hospice

		Religiosity	Perception	Intent = Hospice
Religiosity	Pearson correlation	1	.167*	-.078
	Sig. (2-tailed)		.038	.335
	Sum of squares and cross-products	269.864	16.174	-15.676
	Covariance	1.764	.106	-.102
	N	154	154	154
Perception	Pearson correlation	.167*	1	-.205*
	Sig. (2-tailed)	.038		.011
	Sum of squares and cross-products	16.174	34.727	-14.727
	Covariance	.106	.227	-.096
	N	154	154	154
Intent = Hospice	Pearson correlation	-.078	-.205*	1
	Sig. (2-tailed)	.335	.011	
	Sum of squares and cross-products	-15.676	-14.727	148.727
	Covariance	-.102	-.096	.972
	N	154	154	154

*Correlation is significant at the 0.05 level (2-tailed).

Findings indicate that there is no relationship between religiosity and intent to use hospice. Religiosity is associated with perception of hospice. There is a noted relationship between intent and perception of hospice. Since both independent variables are not associated with intent to use hospice (DV), there is no mediation (Table 18). It was determined that there was no relationship between intent to use hospice and religiosity. Mediation would require both independent variables to be associated with the dependent variable. After review of the data, it was determined that the perception of hospice does not mediate African American religiosity and intent to utilize hospice (Table 17). For research question 4, I accepted the null hypothesis.

Table 17

Regression of Religiosity, Perception, Intent

Model		Unstandardized coefficients		Standardized coefficients	*t*	Sig.	95.0% confidence interval for B	
		B	Std. error	Beta			Lower bound	Upper bound
1	(Constant)	2.607	.351		7.435	.000	1.914	3.299
	Religiosity	-.034	.060	-.045	-.561	.576	-.152	.085
	Perception	-.408	.167	-.197	-2.445	.016	-.738	-.078

Note. Constant, religiosity, perception.

Summary

Chapter 4 has provided a detailed presentation and analysis of the survey results. The statistical analysis that was conducted for this study does support that there is a relationship that exists between religiosity and perception of hospice. The data does support that there is a relationship between intent to use hospice and perceptions of hospice. There is no support of a relationship between religiosity and intent to use hospice. There was also no statistical significance to support the idea that perception of hospice mediated intent to use hospice or religiosity. Since the previous findings indicate no relationship between intention to use hospice and religiosity; there was no evidence that perception mediated an association between religiosity and intent to use hospice. In conclusion, there was a poor model fit for RSQ1, RSQ2, and RSQ3. The null hypothesis for RSQ1, RSQ2, and RSQ3 were rejected. The null hypothesis for RSQ4 was accepted. A discussion of social change implications, interpretations of the findings, limitations related to the study and recommendations for future research of African American hospice use, and intent to use hospice services are discussed in chapter 5.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this study was to determine if an association exists among religiosity, perception of hospice, and African American intent to use hospice services. As the African American population has continued to increase, the rate of hospice representation has remained relatively unchanged. African Americans continue to have low rates of hospice use, with an enrollment rate of 8.7% (NHPCO, 2010). This chapter includes interpretation of the findings, limitations of the study, recommendations, implications for social change, and the study conclusions.

I used a cross-sectional quantitative analysis to examine factors associated with intention to use hospice. The study was conducted online using Survey Monkey to survey African American adults age 18 and older from the National Oklahoma City Douglas High School Alumni Association (NOCDHSAA). There were 154 surveys received from participants who met criteria for inclusion and submitted complete surveys.

Summary of Study Findings

Four hypotheses were tested in this research study to identify whether there was an associated correlation among religiosity (independent variable), perception of hospice (mediator), and hospice use (dependent variable) among a sample of African Americans.

- $H1_0$: There is no association between religiosity and African American perceptions of hospice.
- $H1_1$: There is an association between religiosity and African American perceptions of hospice.

The null hypothesis was rejected. There was a significant relationship identified between religiosity and perceptions of hospice (*B* = .179, *p* = .041). The multiple regression analysis did, however, identify that reported levels of religiosity may not have been the only variable impacting the perception of hospice. The score may have been affected by another variable that was not identified. Based on these results, it was not clear whether a significant relationship existed between religiosity and perceptions.

- $H2_o$: There is no association between intent to use hospice and perception of hospice.
- $H2_1$: There is an association between intent to use hospice and perception of hospice.

The null hypothesis was rejected. The poor model fit did not indicate the factors impacting intent. Intention to use hospice and perception of hospice were negatively correlated. As the perception of hospice scores increased, the reported intent to use hospice decreased. Younger participants were also noted to have less favorable perceptions of hospice. This result was not anticipated, and there were no previous studies found that provided data to support or refute these findings addressing the relationship of intent to use hospice and perception of hospice.

- $H3_o$: There is no association between religiosity and African American intent to use hospice.
- $H3_1$: There is an association between religiosity and African American intent to use hospice.

The null was rejected. There was no association between religiosity and intent to use hospice. As stated earlier, it was noted that as participant age increased, the reported level of religiosity increased. It was also noted that the younger the participant, the less likely the participant was to report intent to use hospice. There was no trend noted that identified a consistent relationship between religiosity and intent to use hospice. Previous literature only provided data concerning generalizable influences of religiosity for African Americans (Austin et al., 2011; Isaac et al., 2007; Lewis, 2007; Quinn et al., 2010; Raghavan et al., 2009). The model also did not explain the elements that may have had a significant effect on participant decision of intent to use hospice.

- $H4_1$: Perceptions of hospice do not mediate the association between religiosity and intent to use hospice.
- $H4_2$: Perceptions of hospice mediate the association between religiosity and intent to use hospice.

The null was accepted. Religiosity was not associated with intent to use hospice. There was a relationship noted between perception and intent to use hospice. In order to review for mediation, both variables would have to be associated with intent to use hospice. Therefore, no mediation was established.

Interpretation

The study findings did confirm a high rate of reported religiosity for African Americans, with 84.1% reporting that religiosity influenced their decisions. This was supported by the literature that identified 70% of African Americans reporting a profession of religiosity (Austin, & Harris, 2011). Due to previous identification of

religiosity as a mainstay for African Americans, I hypothesized that a relationship would be identified between religiosity and intent to use hospice. There was no association noted. The lack of evidence to support a relationship could be related to the definitions of terms such as *religiosity*, *perception*, and *intent* not being disclosed to the participants. Survey questions addressing religiosity could have also been more vague than intended. I believe that the negative response of intent (48.1%) in the study may be related to poor knowledge of hospice and the belief that religion has a positive impact toward healing. Literature has identified that many African Americans have reported relying on their religious faith for healing and deliverance of illness (Hanson, 2009; Johnson et al., 2009). Therefore, those who are religious may not see the benefit or need for hospice and decide not to use these services.

Earlier literature appeared to use the religiosity term as a possible catch all categorical word, that encompassed any descriptor that could not be specifically identified as knowledge deficit, poor access, mistrust, underrepresentation of minority professionals, or culture (Enguidanos et al., 2011; Fishman et al., 2009; Haas et al., 2007; Volandes et al., 2007; Washington et al., 2008; Yancu et al., 2010). The study supported that the religiosity term did not give detailed description of what the barrier encompassed. The other potential problem is that religiosity seemed to be addressed and was also described within what could be considered culture. Previous studies did not clearly define, or distinguish factors that were considered part of the identified barrier. I also noticed that terms of religiosity were used whenever an unexplained preference was

identified. This may also make it difficult to determine the true effect of religiosity and the perception of hospice on intent to use hospice.

Data from this study did indicate a correlation between perception of hospice and intent to use hospice. It was also noted that the older the reported participants' age, the more likely participants were to report their level of religiosity as extremely high. This is in keeping with Quinn et al. (2010), who found that religiosity increased with age. It was noted in this study that the younger the age of the participants, the less likely they were to express a desire to use hospice. One possible reason for this finding is that end of life care is not a thought for most young adults. This might be due to poor exposure to death and dying. There may also be poor experiences with illness, which foster a lack of concern or interest in end of life choices. There also is an inherent perception about death in most societies whereby end of life concern is reserved for the elderly. However, the odds of needing hospice services increase with age. This reality may prompt some discomfort about the subject of end of life care, resulting in African Americans using their claim of religiosity to excuse them from making a decision about intent.

Participants who had a positive perception of hospice were more likely to report intent to use hospice services. There was a low report of participant intent to use hospice. However, there was a high rate of positive perceptions, with hospice being seen as valuable, $n = 147$ (95.5%). As the scores for perception of hospice were more favorable, reports of intent to use hospice services decreased. This may have resulted from previous situations or undisclosed information driving participant perception. If a participant had any experience, positive or negative, with hospice, this could have impacted perception.

Because hospice is generally seen as a noble service provided to the terminally ill, most people may not be willing to report negative views without an experience. In this study, it is possible that very few participants had any experience with hospice, thereby indicating a high rate of positive results for the perception of hospice.

In this study, I used TRA as my theoretical framework to assess likelihood associated with hospice. It is questionable whether planned intent reliably forecasts actual actions where the use of hospice is concerned. My findings from this study will offer the first insight into the barriers that impact intentions to use hospice for this population. The lack of information available on associations of African Americans' intent to use hospice, perception of hospice, and religiosity means that data from this study could not be validated with the use of findings from previous studies.

Limitations of Study

The limitations of this study may have impacted the results that were obtained. The participants may or may not have been terminally ill at the time of participant survey completion. Convenience sampling also occurred through one organization and was completed online, possibly affecting the representation of all demographics adequately or accurately. According to the United States (U.S.) Census Bureau (2014), 32% of African Americans are married, 52% of the African American population makes under the median income of $34,598, and 18.7% have at least a bachelor's degree. In this study, 67% of participants were married, which was a larger representation of the African American married population. Fewer than 30% of participant incomes were below the reported median income, and 100% of participants had at least a high school diploma,

with 48% reporting at least a bachelor's degree. The higher education levels, higher incomes, and higher rate of "married" marital status could have also impacted the response selections related to stability and understanding. The data collection method may have eliminated the possibility of getting input from those who did not use computers, or had no access to the Internet. There was no follow up with participants related to responses provided to survey questions. This study only assessed intent to use hospice and not actual hospice use. Another limitation was that statistical relationships identified could only be related to the actual participants and were not generalizable to the African American population, due to low significance.

Participants may not have provided honest answers identifying their true feelings and may have given what they considered socially acceptable responses to the survey questions. The level of participant understanding of hospice was not assessed. Participant interpretation of the study questions may also have varied from my interpretation. Current life events at the time of the survey might have impacted participant response. There was also the limitation of not knowing why some participants did not complete the survey. Because there have been little to no data collected about this topic, there is the possibility of unreliable or insignificant data results.

Recommendations

In this study, there were unexpected results that were not anticipated. Study results identified no relationship between religiosity and intent to use hospice. A poor model fit was also indicated. The low significance of study results led to questions that pertain to recommended future studies. This study has revealed a need for more research

on unidentified factors and barriers that may prevent intent to use hospice, identification of whether barriers to hospice are different by region or race, investigation of how age impacts religiosity and intent to use hospice, and determination of the prevalence and ranking of the known barriers to hospice use.

For future studies, I would recommend an analysis of all races and the perception of hospice, religiosity, and intent. Additional research would provide a better understanding of the associated barriers and help to determine how African American perceptions of hospice vary, if at all. I would also suggest focused studies with hospice-affiliated professionals, patients who have made a decision to use hospice services, and community group discussions that allow for follow up and clarification of participant responses. There also needs to be more research conducted on religiosity as an actual barrier to hospice and other potential barriers not identified in this study. It would also be beneficial to identify the ranking order of reported barriers to hospice use. An extended study to compare intent with actual behavior of hospice use would also be beneficial in understanding the impact of intent on decisions.

As reported in Chapter 2, there is limited published literature on the barriers to hospice use by African Americans. Many publications have cited religiosity as a barrier to hospice services. The literature repeatedly identified poor knowledge, lack of access, mistrust, poor minority representation, culture, and religion as barriers to hospice (Chilton et al., 2008; Connor et al., 2008; Hanson, 2009). Of the barriers identified in the literature, religiosity has been cited as an important factor and catalyst for African American culture and many aspects of African American life (Chilton et al., 2008;

Hanson, 2009; Johnson et al., 2009; Lee et al., 2007; Yancu et al., 2010). There has been no study that clarifies these barriers or gives clear identification of the implications that define these reported barriers.

Implications

Addressing the association of religiosity, perception of hospice, and African American intent to use hospice has possible social change implications in that it may prompt the implementation of interventions and initiatives that improve quality of life for all patients, effect a decrease in general healthcare expenses, and promote revisions to current end of life care policies. Focus on the association of these reported barriers and African American intent may promote discussion within hospice agencies and national hospice organizations about the barriers to service, the disproportionate use of hospice by African Americans, and how to improve service provision to this underserved population. These results can be discussed and shared with hospice professionals for education and to encourage a discussion about experiences and associations that may have been noted to influence African American decisions to use hospice and the associations noted with religiosity and perception.

There is also a need for community review to discuss the affect that religiosity and perception have on African Americans who opt to use hospice services. Those who have selected hospice may provide insight into the extent to which religiosity and perception influenced their decision. These discussions may also provide additional data and detail concerning other barriers that have not been identified but have been found to correlate. This study has the potential to promote a review of hospice with cultural

implications and propel the discussion of hospice forward in all communities. This study also has the possible social change implications of increased public awareness of hospice services, awareness of barriers to hospice use, and identified correlations of African American perceptions of hospice services, religiosity, and intent to use hospice.

Conclusion

There continues to be poor African American representation of hospice use, while African Americans continue to have the highest nonuse rate at 8.7% (NHPCO, 2010). Barriers to hospice use have been repeatedly identified as poor knowledge, mistrust, culture, and religion (Chilton et al., 2008; Connor et al., 2008; Hanson, 2009). Furthermore, there remains a deficit of published data that have addressed the correlation of African American hospice use and reported barriers. Fishbein and Azjen's (1975) TRA was selected as the theoretical framework for identification of the association of religiosity, perception, and intent to use hospice.

There continues to be poor or absent data to explain the rationale for low African American hospice use rates. This study could bring more attention to the possible effects of religiosity, perception of hospice, and intent to use hospice, thereby increasing public awareness of hospice and increasing education of hospice professionals on the effects of barriers to hospice use. This research is a necessary step toward building the discussion needed to address quantification of religiosity, perception of hospice, and the association with intent to use hospice services. A need for future study of religiosity as a barrier and its association with intent to use hospice has also been identified.

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Appendix A: AARP Letter of Permission

My name is LaTrina Frazier. I am a doctoral student at Walden University. I am in the process of planning my research for the completion of my dissertation. My study is over the predictability of hospice utilization and the perspective of end of life care. I would like to request to use your End of Life Care Survey for my study.

I look forward to hearing from you.

Respectfully,

Of course. Please use it with attribution to AARP. All that we request is proper citation in your work. Best wishes for your success in this research.

Rachelle L. Cummins
Research Director
AARP Research & Strategic Analysis

Appendix B: National Oklahoma City Douglass High School Alumni Association Permission

Hi K. I noticed that you were the person that approved membership to the DHS alumni. I am in the dissertation portion of completing my PhD. Who would I get permission from the Alumni to have you post a link to my survey on the DHS site?

- Friday

4:48am

You can have us post it

- Saturday

12:40am

LaTrina Frazier

Ok. Thanks. I just needed to have written permission. Thank you so much!

Appendix C: Religiousness Survey Permission

sure.

____

Sheena S. Iyengar

Author of The Art of Choosing

-----Original Message-----

Message Body:

Hello Dr. Iyengar

My name is LaTrina Frazier. I am a Doctoral student at Walden University. I am in the process of planning my research for the completion of my dissertation. My study addresses Hospice utilization, and religiosity. I would like to request permission to utilize your religiousness measure tool for my study. I am specifically interested in the portion that assesses religious involvement and religious influence.

I look forward to hearing from you,

LaTrina D. Frazier

Appendix D: Hospice Perception Survey Permission

Hi Latrina,

We can provide you with our survey tool. John and I are at GSA right now and we can get it to you early next week.

Dan

Hello Dr. Van Dussen

My name is LaTrina Frazier. I am a Doctoral student at Walden University. I am in the process of planning my research for the completion of my dissertation. My study addresses Hospice utilization, perception and religiosity. I would like to request permission to utilize your perception survey tool for my study. I am specifically interested in the portion that assesses perception of hospice care.

I look forward to hearing from you,

Appendix E: Letter of Invitation

Dear XXXX

You are invited to take part in a research study on end of life care choices and perceptions. The researcher is inviting African American adults over the age of 18 to participate in the study. This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named LaTrina D. Frazier, who is a Doctoral Student at Walden University. This research is overseen by JaMuir Robinson, PhD who is the dissertation chair.

Background Information:

The purpose of this study is to identify any correlations of end of life care choices and barriers that have been linked with those choices.

Procedures:

If you agree to be in this study, you will be asked to:

> Complete and submit the survey via the internet, privately and independent of assistance.
>
> The survey will take approximately 20 minutes to complete.
>
> Completion and submission of the survey will imply consent to participate in the survey. You will be directed to the survey by clicking the link listed at the end of this consent form.

Voluntary Nature of the Study:

This study is voluntary and anonymous. Your decision of whether or not to participate in the study will be respected. No results from the study's findings will make it possible to determine participant identity. If you decide to participate in the study now, you can still change your mind later. You may stop at any time. The information obtained from this research will only be used in this study.

Risks and Benefits of Being in the Study:

Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as emotional triggers of sadness or reflection of past or present life situations. Being in this study would not pose risk to your safety or physical wellbeing. The topic of discussion could be difficult for participants. The National Hospice and Palliative Care website (www.nhpco.org) is available for additional hospice information and to locate local support groups in your area.

The potential benefits of this study will be the ability to fill gaps associated with end of life care choices and a greater idea of self-perceptions and awareness.

Payment:

No payment will be given for participation in this survey.

Privacy:

Any information you provide will be kept anonymous. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not collect your name or ask for information on anything that could

identify you in the study reports. Data will be visible to the researcher only and will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions:

If you have questions about this study, you may contact LaTrina D. Frazier or Dr. JaMuir Robinson at the emails listed below. If you have any questions about your rights as a research participant, you may contact Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is 1-800-925-3368, extension 3121210. Walden University's approval number for this study is **IRB will enter approval number here** and it expires on **IRB will enter expiration date.**

Please print or save this consent form for your records.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By clicking the link below, I understand that I am agreeing to the terms described above. https://www.surveymonkey.com/s/K5Y9CQ7

Sincerely,

LaTrina D. Frazier
Doctoral Candidate
Walden University
latrina.frazier@waldenu.edu

JaMuir Robinson, PhD
Walden University
100 Washington Avenue South, Suite 100
Minneapolis, MN 55401
jamuir.robinson@waldenu.edu

Appendix F: AARP End of Life Care Survey

For each of the following statements select the choice that best identifies the extent of your agreement or disagreement as it relates to your feelings and opinions about end of life choices and decisions.

AARP Sampled Survey Questions

1. Advance directives allow people to make their health care choices known in advance of an incapacitating illness or death. Which of the following advance directives and other pre-plans have you heard about and completed?
   Have heard about and completed; Have heard about but not completed; Have not heard about; No response
   a. A Health care Power of Attorney (HCPA) in which you name someone to make decisions about your health care in event you become incapacitated
   b. A living will in which you state the kind of health care you want or don’t want under certain circumstances
   c. A will or last will and testament that controls how your assets are to be distributed
   d. Funeral or burial pre-plans in which you plan or purchase in advance any goods or services for yourself
   e. Signing up to have your organs and/or tissue donated after you die for use by others in need of transplants
2. Whether you have completed any advance directives/pre-plans or not, with whom have you talked about your wishes for care at the end of your life?

Spouse/Partner; Family; Friends; Lawyer; Primary Physician; Clergy; Other; Have not talked with anyone

3. How important would each of the following be to you when dealing with your own dying?

   Very important; Somewhat important; Not very important; Not at all important; Not sure; No response

   a. Family/Friends visiting you
   b. Being able to stay in your home
   c. Honest answers from your doctor
   d. Comfort from religious/spiritual services or persons
   e. Knowing medicine was available to you
   f. Planning your own funeral
   g. Being able to complete your will
   h. Fulfilling personal goals/pleasures
   i. Reviewing your life history with your family
   j. Having health care professionals visit you at your home
   k. Getting your finances in order
   l. Understanding your treatment options
   m. Giving to others in time, gifts, or wisdom

4. How important are each of the following to you when you think about dying?

   a. Being physically comfortable

   b. Being free from Pain

c. Having things settled with the family

d. Being at peace spiritually

e. Not being a burden to loved ones

f. Knowing how to say goodbye

g. Having a sense of your own worth

h. Being off machines that extend life such as life support

5. Have you heard of Hospice services?

    a. I have never heard of hospice services ------→(Skip to Question 13)

    b. I have heard a little about hospice services

    c. I have heard a lot about hospice services

    d. No response

6. How did you learn about hospice services?

    a. I know someone who used hospice services

    b. I have used hospice services myself

    c. I am/ was a hospice volunteer

    d. I heard from a health care professional

    e. I read literature/newspaper /TV/radio/ other media

    f. I heard from others

    g. No response

7. If you were dying would you want hospice support?

Yes; No; Don't Know /Not sure; No Response

8. Would you be interested in hearing more about hospice services?

a. Yes

b. No

c. Not Sure

d. No response

Appendix G: Religiousness Measure

Complete this survey by answering the questions using the response that best describes you and your belief system.

1. How important would you say religion is in your life?

1	2	3	4	5	6	7
not at all important						extremely important

2. How much influence do your religious beliefs have on the important decisions of your life?

1	2	3	4	5	6	7
none of my decisions			some of my decisions			all of my decisions

3. How much influence do your religious beliefs have on what you wear?

1	2	3	4	5	6	7
not at all influential			somewhat influential			extremely influential

4. How much influence do your religious beliefs have on what you eat and drink?

1 2 3 4 5 6 7

not at all somewhat extremely

influential influential influential

5. How much influence do your religious beliefs have on whom you associate with?

1 2 3 4 5 6 7

not at all somewhat extremely

influential influential influential

6. How much influence do your religious beliefs have on what social activities you undertake?

1 2 3 4 5 6 7

not at all somewhat extremely

influential influential influential

Appendix H: Hospice Perception Survey

The following questions ask about your attitudes toward Hospice care in general.

	Strongly agree	Mildly agree	Mildly disagree	Strongly disagree
1. I would use Hospice care.	**0**	**1**	**2**	**3**
2. I would recommend Hospice care for a family member.	**0**	**1**	**2**	**3**
3. I would start a discussion about Hospice care with my physician.	**0**	**1**	**2**	**3**
4. I would start a discussion about Hospice care with my religious leader.	**0**	**1**	**2**	**3**
5. Not-for profit status of Hospice care would influence my choice of care if I needed it.	**0**	**1**	**2**	**3**
6. I think Hospice care is important.	**0**	**1**	**2**	**3**
7. For profit status of Hospice care would influence my choice of care if I needed it.	**0**	**1**	**2**	**3**
8. Hospice care is only about death.	**0**	**1**	**2**	**3**
9. Hospice care is about pain management.	**0**	**1**	**2**	**3**
10. Use of Hospice is seen as giving up.	**0**	**1**	**2**	**3**
11. Hospice provides a valuable service.	**0**	**1**	**2**	**3**
12. Hospice care is expensive.	**0**	**1**	**2**	**3**

Appendix I: Demographic Survey

About You

1. Do you self-identify as African American?

Yes No

2. In general, how would you rate your own health right now?

-Excellent; Very good health; Good health; Fair health; Poor health; No Response

3. State your age in years at this time.

____

4. Are you …?

Male, female

5. What is your current marital status?

Single, Never married; Married; Living together as if married; Separated; Divorced, Widowed

6. What is the highest level of education that you completed?

Less than high school; High School graduate or equivalent; Some College or technical training; College graduate; Post graduate or professional degree

7. What was your annual household income?

Less than $20,000; $20,000 to under $40,000; $40,000 to under $60,000; $60,000 to under $80,000; $80,000 or more

Appendix J: Participant Survey

About You

1. In general, how would you rate your own health right now?

   -Excellent; Very good health; Good health; Fair health; Poor health; No Response

2. Are you …?

   Male, female

3. What was your age at your last birthday?

   18-29, 30-42, 43-55, 56-65, 65+

4. What is your current marital status?

   Single, Never married; Married; Living together as if married; Separated; Divorced, Widowed

5. What is the highest level of education that you completed?

   Less than high school; High School graduate or equivalent; Some College or technical training; College graduate; Post graduate or professional degree

6. What is your race?

   African American; Caucasian; Asian; Native American or Alaskan Native; Hawaiian or Pacific Islander; other

7. What was your annual household income?

   Less than $20,000; $20,000 to under $40,000; $40,000 to under $60,000; $60,000 to under $80,000; $80,000 to under $100,000; Greater than $100,000

For each of the following statements select the choice that best identifies the extent of your agreement or disagreement as it relates to your feelings and opinions about end of life choices and decisions.

8. Advance directives allow people to make their health care choices known in advance of an incapacitating illness or death. Which of the following advance directives and other pre-plans have you heard about and completed?

   Have heard about <u>and</u> completed; Have heard about but <u>not</u> completed; Have not heard about; No response

   a. A Health care Power of Attorney (HCPA) in which you name someone to make decisions about your health care in event you become incapacitated
   b. A living will in which you state the kind of health care you want or don't want under certain circumstances
   c. A will or last will and testament that controls how your assets are to be distributed
   d. Funeral or burial pre-plans in which you plan or purchase in advance any goods or services for yourself
   e. Signing up to have your organs and/or tissue donated after you die for use by others in need of transplants

9. Whether you have completed any advance directives/pre-plans or not, with whom have you talked about your wishes for care at the end of your life?

   Spouse/Partner; Family; Friends; Lawyer; Primary Physician; Clergy; Other; Have not talked with anyone

10. How important would each of the following be to you when dealing with your own dying?

    Very important; Somewhat important; Not very important; Not at all important; Not sure; No response

    n. Family/Friends visiting you
    o. Being able to stay in your home
    p. Honest answers from your doctor
    q. Comfort from religious/spiritual services or persons
    r. Knowing medicine was available to you
    s. Planning your own funeral
    t. Being able to complete your will
    u. Fulfilling personal goals/pleasures
    v. Reviewing your life history with your family
    w. Having health care professionals visit you at your home
    x. Getting your finances in order
    y. Understanding your treatment options
    z. Giving to others in time, gifts, or wisdom

11. How important are each of the following to you when you think about dying?

    a. Being physically comfortable
    b. Being free from Pain
    c. Having things settled with the family
    d. Being at peace spiritually

e. Not being a burden to loved ones

f. Knowing how to say goodbye

g. Having a sense of your own worth

h. Being off machines that extend life such as life support

12. Have you heard of Hospices?

    1. I have <u>never</u> heard of hospice services ------→(Skip to Question 13)
    2. I have heard <u>a little</u> about hospice services
    3. I have heard <u>a lot</u> about hospice services
    4. No response

13. How did you learn about hospice services?

    h. I know someone who used hospice services

    i. I have used hospice services myself

    j. I am/ was a hospice volunteer

    k. I heard from a health care professional

    l. I read literature/newspaper /TV/radio/ other media

    m. I heard from others

    n. No response

14. If you were dying would you want hospice support?

Yes; No; Don't Know /Not sure; No Response

15. Would you be interested in hearing more about hospice services?

    e. Yes

    f. No

g. Not Sure

h. No response

i. Complete this survey by answering the questions using the response that best describes you and your belief system.

16. How important would you say religion is in your life?

1 2 3 4 5 6 7

not at all important — extremely important

17. How often do you read holy scripture?

more than once a day; b. once a day; c. more than once a week; d. once a week; e. more than once a month; f. less than once a month

18. How often do you pray?

a. more than once a day; b. once a day; c. more than once a week; d. once a week; e. more than once a month; f. less than once a month

19. How often do you attend religious services and activities?

a. more than once a day; b. once a day; c. more than once a week; d. once a week; e. more than once a month; f. less than once a month

20. How much influence do your religious beliefs have on the important decisions of your life?

1 2 3 4 5 6 7

none of my some of my all of my

decisions decisions decisions

21. How much influence do your religious beliefs have on what you wear?

1 2 3 4 5 6 7

not at all somewhat extremely

influential influential influential

22. How much influence do your religious beliefs have on what you eat and drink?

1 2 3 4 5 6 7

not at all somewhat extremely

influential influential influential

23. How much influence do your religious beliefs have on whom you associate with?

1 2 3 4 5 6 7

not at all somewhat extremely

influential influential influential

24. How much influence do your religious beliefs have on what social activities you undertake?

1 2 3 4 5 6 7

not at all somewhat extremely

influential influential influential

The following questions ask about your attitude toward hospice care in general

25. I think Hospice care is important.

0	1	2	3
Strongly agree	Mildly Agree	Mildly Disagree	Strongly Disagree

26. Hospice care is only about death.

0	1	2	3
Strongly agree	Mildly Agree	Mildly Disagree	Strongly Disagree

27. Use of Hospice is seen as giving up.

0	1	2	3
Strongly agree	Mildly Agree	Mildly Disagree	Strongly Disagree

28. Hospice provides a valuable service.

0	1	2	3
Strongly agree	Mildly Agree	Mildly Disagree	Strongly Disagree

29. Hospice care is expensive.

0	1	2	3
Strongly agree	Mildly Agree	Mildly Disagree	Strongly Disagree

Curriculum Vitae

LaTrina D. Frazier

Education

PhD Candidate, Health Science, Walden University, Minneapolis MN Expected Completion date: May 2014.

MHA, Health Care Administration, University of Phoenix, Phoenix AZ, 2005.

BS/BA, Business Administration, University of Phoenix, Phoenix AZ, 2002.

AAS, Associates of Nursing Science, Rose State College, Midwest City, OK, 1997.

Professional Experience

May 2014- Present	Administrative Programs Manager, Home Services Division Oklahoma State Department of Health
August 2006-October 2013	Hospice Clinical Director, Excell Home Care and Hospice
February 2002-Present	Online Instructor, Health Care Administration University of Phoenix
May 2008-August 2011	Certified RN Case Manager/ Back up Supervisor, Excell Private Care Services
February 2005-August 2006	Certified RN Case Manager, CHC Girling Health Care
June 2005-May 2006	Patient Care Coordinator, Autumn Bridge Hospice
April 2001-June 2005	On Call Nurse, Good Shepherd Hospice

August1994-April 2001	Charge Nurse, Assistant Director of Nursing, Skyview Nursing Center
January 1993-August 1994	Direct Care Staff Floor Supervisor, Cerebral Palsy Handicapped Center

Professional Accomplishments